

Coffee Break with Dave Jackman

Geoff Allix

So joining us on this episode of the Living Well with MS Coffee Break is Dave Jackman. So Dave, welcome to Living Well with MS Coffee Break.

Dave Jackman

Geoff, nice to be here.

Geoff Allix

We're very glad to have you on our program. So the purpose of the Coffee Break is to get to know members of the OMS community from around the world. And you're in the hot seat because you've been featured initially in the OMS Stories of Hope. And also you've contributed to the Overcoming Multiple Sclerosis Handbook in the progressive MS chapter. So before we go on to the MS side of things, could you tell us a bit about your normal day-to-day life?

Dave Jackman

Well, I'm retired now. I was a teacher and retired 11 years ago, just before my diagnosis. And so these days, I spend a chunk of my mornings, communicating, checking emails, responding to them. I run an Airbnb studio just next door, I deal with the admin for that. I'm also treasurer of my local Cricket Club, I was a keen cricketer. I'm not quite as fit these days. But I've always got stuff that had to do with with the cricket club and many dealings with that. In the afternoons my wife Rae and I usually go out with a dog. We have a Cavalier King Charles Spaniel called Dexter, who's named after the serial killer. I love to travel so I'm always checking out new places to visit. We've done home exchanges for over 25 years now. We love doing that. And being retired offers us the freedom to do a lot more traveling. Walking in some sunshine, somewhere abroad is a bit better than some dreary dog walks in the Scottish gloom, I can tell you. I started to do dog sitting, which means we look after people's dogs from anywhere in the world. So we're still traveling a lot and getting out and about.

Geoff Allix

So you've mentioned you were diagnosed about 11 years ago, I think you said so how was that initially? And how did you deal with it?

Dave Jackman

I was diagnosed in October 2011. Yeah, this was going back. I retired in the August of 2011. So that was two months later. After that I was diagnosed with with MS. And I kind of knew something wrong, but I wasn't too sure about you know what it was. I can remember walking along the school corridors and finding myself staggering to the side from things that they hide to support myself on the wall when I felt that's a bit odd obviously, but I had no idea of what was causing that. But that was about the only sort of feeling that anything was wrong. But there, we knew something was wrong. So my wife

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and I did a lot of research online. Because many of the symptoms of MS are similar to those of motor neuron disease, right, so I kind of feared the worst. We had two friends who suffered from motor neuron disease, who sadly passed away rather quickly after diagnosis. So when we actually got the diagnosis of MS, it was a bit of relief to be honest. The outcome long term makes it look a bit bleak. When speaking to the neurologist, when he was explaining the loss to me, I wanted to know what the sort of long term prognosis was. Because as with many people, I think my wife and I, we knew people with MS. They tended to be in wheelchairs and not very well. And I wasn't feeling too bad at that time. The feeling that I was going to end up in a few years down the line, obviously wasn't too good. So I was really pushy with him and said, Look, tell me straight, what do you see happening to me or the next 5, 10 years? I can take it, just tell me so I can make plans and you know, get myself sorted out physically and psychologically, I suppose. And he was good. He said I could expect to follow the normal sort of progress as he was familiar with it. He would see me requiring a walking stick, that'd be within about three years or so. And a wheelchair another three years after that. So that was what was in my mind, but I felt I wasn't downcast with that. Again, I still felt I was actually not too bad at that precise moment in time. And although that was prognosis, I was happy that he was honest enough to give me that I wasn't sort of downcast. Rae was a lot more worried. She was a bit more stress than I was to be honest. But at that point, I wasn't too bad. I thought I could handle it.

Geoff Allix

I know what you mean. My reaction was, "I haven't got a brain tumor." That was the thing I thought I might have. And you think, there are a lot worse things it could be. You've got all these weird symptoms, what could be causing that? Is there something going on in your brain? And yeah, could be motor neuron disease, could be cancer in the brain, could be all sorts of things. So actually, although it's not a good diagnosis is yeah, there are a lot worse things. And so when did you come across the OMS program?

Dave Jackman

With a lot of research, before before diagnosis, and then afterwards, obviously. And Rae was always ahead. Rae's quite obsessive. And she really got into it, really spent a lot of time researching it. Obviously did her best to helped me. And she kept saying, there's all this research, but I can't find anything positive out there. Because all the literature was feeling negative. That's not helpful when you're looking for something to bump you up and give you some inspiration that that wasn't there. She'd just gone to the local library. And there was nothing she said positive that she could find, apart from Judy Graham's book on self management. But even that offered an awful lot of different options. But at least there was some sort of positivity in what you were seeing. What it didn't mention was Roy Swank's work. And that got us into looking at what he'd done what he'd been involved with. And that that was, to me, it was much more interesting. That not only was a positive, this is somebody that spent that amount of time 30, 40 years doing all that work. And what he was coming out with is that for somebody like me, that was a major step and so we got into Swank, and started to follow his his diet and lifestyle. I was still dubious, because despite what I feel about Swank, the professionals still didn't seem to back it. I mean, I was going to doctors, but never did they ever say, oh follow Swank.

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Again, because I had PPMS there was precious little out there in terms of drugs. To me, what I was researching was like the only hope. So anything I can grab a hold would be beneficial. So Swank seemed a good bet to follow. But why was nobody else backing it? Why was nobody else reading about it? So that put a wee bit of damper on it. But I think our attitude was that if we follow Swank, then the most we're going to do is live a healthier lifestyle. Whether or not, we're going to be healthier. So let's go for it and if we do get benefits, great. After a while, we came across the OMS lifestyle. Again, that seemed more up to date version of what Swank had been doing. There's obviously more research that Professor Jelinek had done. Swank combined with what Jelinek was seeing seemed a good path to follow. Again, I'm not very good at changing stuff, but my wife has denied me to do anything. And she was a great source of strength because she pushed me and pushed me when I was really doubting it. But I got into the Swank, slowly. But there did seem a lot of sense in it.

Geoff Allix

That's what my neurologist said that to me. So worst case scenario, it's going to make you a lot healthier, and it will reduce your risk of getting heart disease, cancer, diabetes, and you really don't want to get those things when you've already got MS. There's no downside then. And he said, no, it's just healthy lifestyle. So there's no downside to living a healthy lifestyle.

Dave Jackman

An annual visit with a neurologist and he would ask how I was getting on, and I'll tell him I was get him on. And I'm sure he was surprised, because he wasn't expecting to see the things he was seeing. And he was seeing me healthy. I was going along and sitting in a waiting room full of people who are struggling to walk their on Zimmer frames or walking devices and wheelchairs. And I was walking down the corridor into his exam room and he's asking me how I was getting on and I'm saying I'm fine. I'm following this and he never commented positively. He said, "oh, well, if that's helping just keep doing it. It's obviously working for you." And that was his attitude, which I thought was really disappointing. And I kind of felt I wish he was a bit more up to date with those things. He'd obviously been doing the job for 20 years or whatever. I didn't want to tell him how to do his job. I feel like he was kind of going through the same things seeing the same things. He could have been a bit more up to date with this sort of his work and his research. However, I kept quiet but I told honestly how I was getting on but I still find it disappointing that he, and the GP as well where not sort of mentioned anything about OMS. When I started I was resistant to change. The program worked really good. I was still hesitant. I thought it was my scientific background. I just feel I need to see evidence in front of my eyes. That makes me say "yes, this is it for me." And so I read what was there and I read what Jelinek was saying. And yeah, it was good. But I hadn't seen anybody that had done this and hadn't seen personally anybody with those positive outcomes and I kind of needed that extra if you like to get really on board. Rae was great with the diet. She's a perfect cook anyway. And she has been trying to get me to eat more health and for years. So the same the carte blanche stuff to try lots of things, half the time I didn't know what I was eating, but of course she would produce something Give it to me and I'll say "what's that?" and she'll say, "do you like it?" And I said yeah, I like that, and then she'll explain what was in it. Okay, I didn't realize that beets were

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quite so tasty. She continue to do that and develop the foods and it was naive on my part, but I didn't realize how good tasting a lot of this stuff was I had of course this belief that vegan or vegetarian foods was bland and not very tasty and while healthy, wasn't exactly inspiring to eat but in fact, she made it that very tasty and each meal I was getting was new and different and I was enjoying it.

Geoff Allix

I think for me, it's getting rid of the processed food. If you cook food fresh, you go back. We've got so used to packet food and it takes away a lot of the flavor and you think actually because I mean it's a lot more effort in cooking food, but actually the food I eat now is much more flavorsome and because it's cooked from fresh ingredients. So I think it's partly that so yeah, I don't really miss the meat side of it. That's not a big problem for me.

Dave Jackman

She bought a Thermomix, you know, the cooking machine. And it meant that she could make much more of the meals from scratch herself. So she was 100% in control of what went in. And yes, you're right, we cut out all that processed stuff. And going back 11 years, we would find it very difficult to find stuff on the shelves, that was suitable. We used to go into the local Sainsbury's and they had a counter there that was "free from" and it was healthy this and healthy that and gluten free and this free and then you looked at the sat. fat level and God it was astronomical. So we were finding it difficult to find stuff at the supermarket. But when we got this Thermomix she was looking at recipes, OMS compliant recipes that she could then make from scratch. And then she was in full control and of what went in. So she knew what was in them what the ingredients were. And she was coming out with all these amazing meals that if she told me years ago that we would be eating chickpea blah, blah, blah. But whatever she was doing, I was really happy so and then you step back and you think well, the stuff I used to like that had meat and dairy. I still love cheese, I used to eat cheese all the time. But when you're given the choice of you can have more cheese or you can walk because if you keep eating cheese, the chances are you're not going to be able to walk it's a pretty good argument, that so I went down the path that she was she was giving me and I thought I was doing okay. But again, there's a doubt in my head. It was me doing this in isolation. And although I felt I was actually getting worse initially. It wasn't until I went to the Launde Abbey retreat in 2013. The week there, I know it's a cliché, but it was life changing. And that was really when I knew this is the path to follow. I came away from that really inspired. And yeah, this is what I was gonna do.

Geoff Allix

And so you talked about diet that seems to be you've adopted that pretty well how about the exercise side of it, because I know you've got a history of volleyball. So tell us a bit about where you've come from in terms of exercise and how you've managed to continue with exercise post diagnosis.

Dave Jackman

Exercise. Yeah, that stand of the lifestyle is never an issue to me at all. I was very active when I was young. I've played cricket for about 40 years. Yeah, when I was younger, I

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played volleyball. I used to do cross country, did a lot rowing. I was always active. It was rare to have a Saturday off not doing some sort of sport for 20, 30 years until about 15 years ago I would have stopped. I was always keen on exercise. I really enjoyed it. So when it came to the OMS lifestyle and talking about exercise I was never going to find this doing exercise an issue. I still do a lot. I can't do running as much but certainly a lot of walking with a dog once a day, something twice a day. If the weather's not good, I can't do the walking then I've got an exercise bike and I do five miles anyway on the exercise bike. I think that's actually more beneficial than walking the dog. The dog's so slow, slower than me, I would hardly call it an athletic experience. I like the bike because you can really push yourself on the bike. I'm gonna get off the bike, I'm tired, and achy. But then about two, three hours later, my legs feel really invigorated again, I feel really up for walking about and doing the normal stuff on the feet. So I really enjoy the exercise bike.

Geoff Allix

And how about the other of the three big pillars, if you like the diet, exercise, and the mindfulness. How about mindfulness, did that come easily?

Dave Jackman

That was the biggest problem. I was one of these people who used to think these crazy people did all this meditation and stuff. But if it helps them, fine. So okay, so this was part of the program. So I was kind of forced into it in a way, I must take this more seriously. I looked at it. I joined Headspace for meditation. So I got really into that every day. I still felt I wasn't doing it right things, I didn't know what I was doing. But again, going to the retreat, we spent an entire day looking at meditation and mindfulness. It was Dr. Craig Hassed that was doing that. And he spoke really well. And he went through all the theory. And then he went through all the effects. And here are example was a few of graphs. And my mathematical brain is registering, I think, yeah, this looks actually possible. I'm still doubting it. But I'm thinking that a lot of people have done this. And a lot of people are getting something out of this. And it's positive. And it's having an effect on their MS. For me as I came away from the retreat, this was one of the things that I was really stimulate to get into. And so yes, I was doing Headspace day after day after day, still not thinking I was doing it right. But I thought it was one of these unconscious things that after a while we were kind of doing it automatically without thinking and that mindfulness thing. Again, I started to get away from here's your session of meditation and mindfulness, it's going to be 30 minutes, concentrate on that and that was it. So I was trying to get away from that and taking it into the rest of the day. So the mindfulness actually became part of the dog walk. Because that was the one point, I was alone with the dog and I was out, there's nobody there. And I'm just walking. And let me do it on my own. And again, because it's so slow that I can take in everything. And I can take in the weather, the traffic, the clothes. We live in a sort of rural village. So there are things going on in the fields. And I started to observe all that, before I would just walk past it without giving it a second glance. And so I started to incorporate mindfulness more in everyday life. It was subconscious. Again, it's one of these things that I never thought about it. I probably thought I couldn't do it. But after a while, I realized I was doing it. So it became an integral part of the day. So I still continue. So that was difficult. It was the hardest bit to get into. But here we are 11 years on and I'm still doing it.

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Geoff Allix

Outside of OMS and MS, you mentioned that you participate in home exchanges and you've got an Airbnb so can you tell us a bit about that, your business?

Dave Jackman

Yeah, again, I retired and then I was hit with the MS diagnosis. I felt kind of limited maybe in what I might be able to do in the future. And we were redecorating. We just moved. We were redecorating the house. And the house had this big garage, slightly bigger than a normal garage, because the people had a car and a motorbike. So the garage was slightly bigger than obviously a standard garage. And we were just talking one day. We moved stuff from the house into the garage while the house was getting redecorated. And I was talking about this garage. This was wasted space. The stuff we were storing in there, we could store more stuff in the house. And then we could make better use of it. And I really mentioned creating a sort of studio, so that our son that lives in California. And we go to see him COVID willing, every year. And if he ever came over, it would be nice to give them somewhere to stay. So they were with us, but they had their own freedom outside of the house, to do their own things that we thought might be an idea. So we started thinking about converting the garage into the studio for our children to come and live with. And then at some point, probably me, but what about renting it and so we started looking at ways we could rent it and we had stayed at Airbnbs, actually on our trip to some of the reunions in England, because it's a long way from where we stay to go to these reunions so we tend to leave the day before and stay at an Airbnb overnight, and then go to the next day. So we had experience of AirBnBs and thought that would be good. I mean, basically it's a place to sleep in the some places that have cooking facilities. But they're all good quality. So we thought we could do this. So we again, did our research and looked around. And of all the companies that we looked at we thought Airbnb was maybe the best one to go through. So we did all the stuff, got all the photographs taken, put it up and move the house up as well on Airbnb as well as the studio. Not because we're greedy, it's just that we thought that the house looked better than the studio. The studio was just one room, the house was quite nice a three bedroom bungalow, it would be more attractive. But then we realized that it also needs a lot more looking after. Because if Airbnb people are coming in, you've got to make it look absolutely fantastic for the new guest. And that was just too much work so we shelved that and just focused on the studio. And it's smaller, it's easier to upkeep. And it's actually been really successful. We've had over 100 5-star reviews over the course of about three years and then that includes one year of COVID, were we basically had nobody. So if you're looking for a visit to Scotland, in a village called Falkland it's got nice palace. It's got nice, attractions. We've got some good cheap accommodation for you.

Geoff Allix

We don't normally advertise. But I think that's absolutely fine. So you've contributed to the Overcoming MS Handbook, this latest book by Professor George Jelinek talking about progressive MS. So how was that working on that project?

Dave Jackman

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Good, the literature that existed on MS tended to concentrate more on relapsing remitting. MS. And so the authors of the book, were quite keen to find contributors that there were suffering from Primary Progressive MS. So I fitted the bill and I was happy to contribute, happy to do so.

Geoff Allix

And you mentioned in your story you mentioned about logging and checklists. So you mentioned that a food log and a symptom checklist. So firstly, how do you go about having a food log?

Dave Jackman

Basically, I just kept a log of what I eat every day. Initially, again, we've been really going through these issues trying out lots of different things. So I wanted to log what I was eating to see if it had any effect. I wasn't expecting it to have like immediate effect that day but in the course of several weeks, perhaps maybe I would feel something different or some change. When I first got MS. And I didn't think that much was wrong with me. I logged what I had wrong with me at the time. I had foot drop, I had, I was a bit wobbly, I had pains in my arms, and my speech was slurring. So I had 3 or 4 symptoms that I knew I had. So I thought that if I logged what symptoms I had, I like working with numbers. So I gave 10 to anything that I didn't have an 9 if I had a week bit of it and so on. So I had this chart that I filled out every day for about three years. I had this numerical chart, and I initially had four symptoms. But gradually, I got more and more symptoms. I had 12 symptoms, not all the same time. But I would log for what I had, which at the height of the day, and how bad I was suffering from it. And I did this religiously every day. And I did the same thing with the food. And I look for what diets are more effective for MS if any. The symptoms checklist, I found that as more and more symptoms crept in, the ones that were already on the list were actually getting worse. And so I had followed OMS, for nine months, and I'm looking at the chart, and I'm worse in 12 symptoms, so I've been following OMS for 9 month, and my symptoms are worse. And I think it's really important to say this to people, that you have to persist because I think it'd be dead easy for me to have looked at that and thought this is a waste of time, I'm going nowhere here. And I although I continue to do the charts, I paid less attention to them. And one day I looked at the charts, I just got such a routine of doing them that I wasn't really concentratin. I was putting in the numbers. And they one day I looked at the numbers. I hadn't looked at them seriously for a couple of weeks. And some of them were actually better. Some of them have actually gone up. And then another week or two later. And I'm looking at the numbers again. And actually, that's quite a few things that are a 10. And I hadn't read it. It seems daft. But I hadn't registered that some of the symptoms on the list, I wasn't suffering from anymore. I think we've got something you know you've got it. Well, you haven't, you don't know what's missing. So that really struck a chord and I thought hey, and so gradually was time of those 12 symptoms 10 of them disappeared. They weren't affecting. I still have issues with walking, I still have issues with I'm a bit wobbly. But some of the other things some of the I would say some of the worst things like bowel and bladder issues and stuff like that, I don't have anymore. And it actually took me a while to register. I didn't have them But here I am 11 years in now, and the walking and the balance yet still have some issues, but I still don't need a stick. And I still don't need a wheelchair. The issues I do have the rate of

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deterioration slowed right now. So yes, it's taken a long time. But please anybody who gets into this persist, persevere. It does take time. It's not an overnight fix. I think people are so used to go to the doctor getting a tablet and expecting wonders, a quick fix. This is not a quick fix. It takes time. But when I look back now there were signs there that I just didn't notice them. Because I was just focusing on "I'm getting worse, I'm getting worse" with this stuff. Yeah, there it was. There was the evidence.

Geoff Allix

I think it might have been Professor Jelinek who said it was like turning around an oil tanker. So it's going in the wrong direction. You can start turning around an oil tanker, it will be still going in the wrong direction for quite a while. Before eventually turns. Nowadays especially I think we expect, take a tablet get fixed, take an aspirin, sorts your headache out, you know, happens straightaway, not, oh, maybe 2, 3, 4, 5 years down the line, you will get better. It's a lot of commitment, if you're going with a lot of faith actually say, I'm gonna make lifestyle changes, and I'll keep doing it, but for years.

Dave Jackman

It does require, I think, a lot of persistence and perseverance. Yep. I get it. I'm not a person of faith. But if I start to see evidence of things, then I could start to believe. And I can understand people starting it, and then losing the will after maybe a few weeks or a couple of months. But it's just so important to persevere and continue. I can't speak for everyone. But I really feel if you continue to persevere with it, you will see the benefit. And then again, as I said, the worst you're going to get is healthier.

Geoff Allix

So you mentioned the Launde Abbey retreat. And you're also involved in reunions for that. So how is that with the reunions? Because it's been, I think it may be 10 years since the retreat. So do you still have regular meetups?

Dave Jackman

I think we all came out of the Launde Abbey retreat really full of vigor and enthusiasm and made such good friends, I think it's actually great to be with people who are going through the same thing as yourself. I think, again, another thing I think a lot of people are trying to follow OMS in isolation. And it's so difficult, you're on your own, you've got to have a partner to back you up. But also you've got a friend, you gotta have somebody else, some other people in your group that understand and are going through the same thing. And so as a collective, we came out of that retreat, inspired, and we didn't want to stop. So a lot of people agreed me up again. And we asked can we do this? And we thought, well, yeah, let's do that. So myself and 3 or 4 others said we'll meet again, we'll organize something. How about a year's time? Yeah, ok so we did that. About five of us got together. And we set about organizing a reunion. And we found a place that would be suitable, and a quiet place. It's got nice surroundings in the country, not unlike Launde Abbey. We didn't want it to be just bang, bang, bang, you know, all MS stuff. But obviously, what some stuff, there's an interesting stuff to be in there. But the main gist of it was to get people back again, and meet. And it was wonderful just to meet people, you haven't seen him for a year. So we all left inspired. And then you don't see them for a year. And then they come back. And you see and I have to say most of them are looking

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great. Some of them have made improvements. Some were still as they were, other's weren't quite so good. To have that number, the vast majority of us looking great and really healthy. And again, I just thought it was more sort of inspiration and confidence that yeah, we're doing the right thing here. But it's so good to be with people going through the same thing. And then again, the people who came all the way from Sweden, Germany, Switzerland, England, Scotland, all over just for the reunion. And it was just the weekend, a couple of days. But again, everybody left with such positivity. That was all a case of we must do this again. So the next year we organized another one. Again with a program with slightly different things to have on the program. Different events, and, again, got a fantastic response. So we just kept it going and so every year we organize another one. And then we started to think, well, this is very successful. Why don't we reach out to people who've been on other retreats? They might be interested and got great feedback again, people wanted to come from other retreats. So we opened it up and over the next 2, 3, 4 years, we're seeing people who hadn't met before. But they brought stuff with them, they brought other information. Things that they'd tried, they'd done it seem to kind of widened, knowledge and experiences. And again, if we just left, so full of positivity, that was a word that I always felt when I left: positivity. And suddenly COVID came along and knocked on his head for a couple of years. But we're, we're planning to have another one in 2023, we've got plans to hold one and me back at Charney Manor in 2023. We've not sent out any of the information yet. It's still in the backroom, stuff like that, but we have booked the place. So it will take place, but we'll let people know in due course,

Geoff Allix

So thank you very much for joining us. There is one final question we always ask, Do you have any key nugget of advice for people, particularly people who are newly following OMS? To adopt the program?

Dave Jackman

I think looking back, the biggest thing I would tell people, is to persevere and take your time. I think it can be really off putting it was to me anyway, to look at the end product. Here you are 100% compliant with OMS. And this is what you've been doing. And this is what you're eating. And if you look at that in isolation, you think I'm never going to get here. I can't do that. But that's not what your thought process should be. Your thought process should be: That's what you're aiming for. What can what can I do now? And that's effectively what we did. We looked at what was on the lifestyle, thought we could make that change and that change. And we can do this. And I can investigate that. So as I said before, exercise was dead easy, really was great with the dietary side of it. Yeah, meditation and mindfulness that was that was probably in the lane for me. And that was something that not come easily. But as I said, when I look back now, I think, I think that's the way to go. I think don't get put off by the end product. Just take your time, and just do one thing, one wee step at a time. And hopefully see the benefit. Okay, I need charts and stuff to see the benefit. Most people probably don't need that. But slowly, you'll see the benefits. Rae's always saying that. Telling me that I'm not 100% compliant, OMS. And I'm not, yet. I keep striving to get there. And I everyday I'm feeling closer. I've been doing it 11 years, I still don't think I'm there. I'm almost there. But I'm much closer than I ever thought I'd get when I started doing this. And that has been

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slow, steady progress, to date to get there. But that would be my advice, take your time and just do one wee thing at a time, just develop one thing, get the benefit from that and move on and just keep adding to it. And again, as I said before, if you never get there, don't stress about it. You've made yourself healthier. And whatever you made, what made things like heart disease and diabetes, you made less possible for you. Because you know, much, much more. So don't stress about getting to this goal 100% OMS. Keep working towards that. And just get there slowly step by step, maybe you'll get there one day, maybe you won't but keep going for and you'll benefit. Come with may.

Geoff Allix

And with that, thank you very much for joining us, Dave Jackman.

Dave Jackman

Right. Well, thank you very much. I enjoyed it. Thanks.

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