

S1E5 Live from Recovering from MS in Edinburgh June 2019

SPEAKERS

Craig Hassed, Pauline, Geoff Allix, Sandra Neate, George Jelinek, Steve, Nora, Phil Startin, Wendy, Linda Bloom, Maria

Geoff Allix 00:00

Support for the Living Well with MS podcast is provided by Overcoming MS, a global charity registered in the United States, United Kingdom and Australia, whose mission is to educate, support and empower people with MS in evidence-based lifestyle and medication choices that can improve their health outcomes. Please visit our website at www.overcomingms.org to learn more about our work and hear directly from people around the world about the positive impact Overcoming MS has made on their lives. Now on to today's episode. Welcome back to the Living Well with MS podcast. I'm your host Geoff Allix, and this special episode is recorded entirely on location in Edinburgh, Scotland, site to a very special one-day event called Recovering from MS: Wishful Thinking or Realistic Optimism. This event took place on Saturday June 8, 2019. With featured guest Professor George Jelinek, founder of the OMS program. Among the 400+ attendees joining George were numerous OMSers, neurologists and other health professionals, as well as hundreds of people from around the world enrolled in the OMS program, myself included. It was a very special day indeed. So I decided to take my mic on the road and have some impromptu chats with some of the many fascinating people in attendance, including Professor Jelinek. I hope you gain as much from snippets of some of these candid conversations as I did. I'm here with Phil Startin, who is a frequent facilitator at OMS events, and who lives in Scotland. Phil is distinct in many ways, including his deep expertise in mindfulness. An additional point of distinction is that Phil has primary progressive MS, rather than relapsing remitting MS, which is the most common form of the condition. Phil, what's it like to have Primary Progressive MS, especially given that until recently, there have been few treatments for it? And how are you finding the OMS approach for people with Primary Progressive MS?

Phil Startin 02:04

Thanks, Geoff. Yeah, I have to admit, when I was on my retreat back in 2013, I got to the end of the retreat, and to the end of the five days, and yes, I had quite a lot of hope. But I also had a little bit of skepticism because George (Jelinek) and Craig (Hassed) and Sandra (Neate) talked a lot about reducing relapse rates, and reducing the severity of relapses as a consequence of following the OMS program, but they didn't talk much about eliminating degeneration, which is kind of one of the key characteristic mechanisms that underpins the progressive form the condition, although it's also there in the relapsing form as well. So I kind of came away thinking, well, actually, if it works, then great. And I tried it. And I've been following OMS now for for a number of years for about six years. And I'm absolutely completely convinced that this has changed the progression of the condition. From my perspective, the trajectory of my MS is different to how it would be if I hadn't been following OMS. I'm

still losing a little bit of function. But I'm certain that my progression and the rate of progression has slowed. Although I've lost some function, in certain areas, I've regained function as well. So some definitely huge benefits, some say some following OMS. I think maybe in some sometimes I do think it's a little bit of a case of two steps forward and three steps back. But at the end of the day I know I'm, doing the right thing. I know it's making a difference. And I absolutely will keep following OMS forever. Thanks very much. I'll tell you look a little bit more mobile than when I last saw you last September. Well, I always take compliments like that, Geoff. No, thank you very much. That's great.

Geoff Allix 03:47

Thank you. It's nearly lunchtime here at the OMS one-day event in Edinburgh. And I'm just snagging Maria, a medical doctor from Santa Cruz, California before she grabs her lunch. Maria, we're hungry to learn how you found out about OMS which sessions you attended today and key takeaways.

Maria 04:07

Well, I didn't find out about OMS until two years ago, I was diagnosed in 1992. So quite a while ago, and I was very exposed to medical literature being a doctor but did not find out about OMS until I stopped working and started looking online and found it. This was the first thing that really made me feel hopeful. So after I found out about OMS, read the book, started doing the diet, started doing all of the principles, just this year went to a retreat in Australia in Yarra Valley, which was fabulous. And so now I feel like I'm pretty knowledgeable, but I really didn't want to miss the chance to meet George. I had never been to Edinburgh. So I decided that I was going to do this and I really feel passionate about bringing this to the United States. Since I'm a doctor, myself and I have seen loads of patients with MS, but did was not aware when I was practicing of OMS. So I want to bring these, this hope and also the possibility of avoiding further symptoms for people to the states. The things I guess the main takeaways for me, I went to the retreat, other things that I've done here, there was one session on the positive effects of the retreats, which I had already kind of been aware of. And that was one of the things that made me feel hopeful is that people actually do better from year to year after the retreat, rather than the usual course with them as people get worse. And people actually get better after the retreat, I found that just amazing and so inspiring. And then the other session that I went to was on mental health. And she, Rachael (Hunter) talked about the importance of resilience with this disease. And I found that very inspiring. And I, I'll be thinking about some of those things that we can do to be more resilient.

Geoff Allix 06:06

I'm catching up with Wendy now who I met last year at an OMS event in Wales. Nice to see you again, Wendy. I was wondering how you're finding the Edinburgh event, which sessions you've been to, and what your thoughts are on what you've learned.

Wendy 06:20

Thanks, Geoff. Yeah, I came in to Linda (Bloom) talking about taking on the mantle of making a charity. That was very inspirational. And George, like big it up for George Jelinek giving us our lives back! That was the whole thing is so important. And so it's supportive of my improved health, nothing but gratitude oozing out to me, which is always good for reducing your cortisol levels. And so that was wonderful. I mean, it's just so good to see George with his family of us, with the tribe, and meeting friends and other thriving OMSers. My breakout sessions were the first one was with Dr. Stewart White, which was

Preventing MS. And that's so important. And it's difficult to get your children, the sisters to keep taking the vitamin D and reducing the saturated fat and it was very truthful, and you know, down to earth, they don't just do what you say, or we don't just do what we know is good for us. But yeah, lots of encouragement and inspiration to take it easy, really. And it's yummy. And then my other very current session so far was with Rachael Hunter, is it? Yeah. Beautiful. Just so beautiful. So honest, so authentic, talking about her experience, and even as a clinical psychologist, not being able to talk yourself out of being devastated by her diagnosis, about realizing that that way, you know, is not a good way to be devastated, but that we can adapt. And be resilient and find ways to ride this invasion in our lives. So there's an image of a tree blown so that it's at a 45 degree angle. It's strong. It's rooted, but it's adapted to the wind and yeah so far, so bloody gorgeous. Thank you very much. I'll have some more things. And then Craig (Hassed) was talking about mindfulness. And neuroplasticity, and epigenetics and all those wonderful things, which, there's no limit to the possibilities. I think we're like building a superhuman race here. Not only helping ourselves, manage MS, but just like, the sky's the limit really. I'm feeling positive.

Geoff Allix 09:50

Thank you very much for that. So I'm talking to Linda Bloom, who's the Chair of the Overcoming MS. Charity. I just wanted to ask you what inspired you to form the charity. So Professor Jelinek obviously we've heard from, and he came up with the science behind it, but what inspired you to actually start the charity of Overcoming MS?

Linda Bloom 10:12

Thanks, Geoff. And thanks so much for doing this podcast. It's fantastic. And we've loved hearing the different episodes. So I was diagnosed with MS 17 years ago. And as I mentioned earlier, it was hit me pretty suddenly and pretty dramatically. So I was bedridden, completely incapacitated. And it was when I was at my lowest and really relying 24/7 on people for care that my sister, who's a doctor, came across Professor Jelinek's book, his first book "Taking Control of MS." And when she read that book, to me, it really made sense. And I felt that this was something that I could do to help myself to take control of what was a pretty uncontrollable situation at the time. So I started following the seven steps and gradually, over time started getting better, continue to get better haven't had a relapse. Now, it's been 17 years. And in fact, my last scan showed that I no longer have any lesions on my my MRI. So it was very exciting. But when I moved to the UK, about 10 years ago, 12 years ago, now I started wondering if people here knew about OMS. It was fairly well established in Australia, which is where I'm from. And after speaking to people, I realize that no one here had heard about OMS and heard about Professor Jelinek. No one really knew anything about lifestyle-based interventions. And I went home one day after an MS Society event. And after asking people there if they knew about it, and had this sort of epiphany moment where I realized that if people didn't know about it, then I needed to do something to change that. And it was a really strong feeling that actually, if I knew about this information, I knew other people in Australia knew about this information, and I didn't share it, then it was actually being really negligent, I felt. And so I felt this kind of responsibility to share the science and the information behind the OMS program. So I had no idea how to do that, or how to go about it, but decided over time to set up a charity. And slowly, slowly, we started running events. And George came over for the first event that we ran in Brighton. Back in 2012, maybe 13. And and it's just grown from there. And it's been incredible and humbling and exciting to see how the charity has taken off, how many people have benefited, and

the amazing team of people we have now spreading the message about OMS. And that recovery is possible.

Geoff Allix 13:02

Thank you very much. And personally, thank you because I think without you as much as Professor Jelinek, then I wouldn't be where I am and discovering OMS. And the benefits it's personally given me so thank you. Right, I'm now with Steve. He's actually a partner of someone with MS. So I wanted to ask how you found the Overcoming MS protocol for a partner of someone with MS and how it's affected you and your family. And and also because you've also been here for today's event. And the key takeaways from today.

Steve 13:34

I think the main thing really for me as a partner with somebody with MS is that we found the program maybe three, four years ago, coming on three, four years ago. And I think what it gave me really was somebody fighting in my corner, while I was watching my partner, you know, for the illness itself. Up until then we were just a team together doing the best we could. But I think when the OMS program came along, what we found is we had a sense of direction, a sense of purpose, and some hope and optimism. And, you know, over the years that's proved to be correct. As far as today's events have gone, I think it's just reinforced the view that, you know, this is a bloody good thing to be proud of. And that if it could reach out, maybe to more partner supporters as well. I think that would be a good thing overall, for the program and for people with MS.

Geoff Allix 14:33

Thanks very much for that. We're coming to the end of the day now. And I've just met Nora, who's someone following the OMS program from Germany. And I just wanted to ask, what session have you been to today? How you found the session today and how you found the OMS program.

Nora 14:56

My first session was with Sandra Neate. Retreat Outcomes for People with MS and Partners. And the other one was Newly Diagnosed: Where to Start Diet and Nutrition with Sam Josephs. And I really enjoyed both sessions. I found the one was Sandra quite interesting because I'm considering doing a retreat. I haven't done a retreat yet. And I just really wanted to know what the benefits would be. And I think from what I've learned today, it's quite convincing to do one to attend one of the retreats in the near future. So I'm hoping to attend one in Europe, because Australia is quite far away. Maybe there might be one in Germany at some point, I don't know. The other session I attended was the one on nutrition, which I also found quite interesting, even though there was very little new things to learn for me. But she gave us some tips on what frying pans to use. How to fry food, what to focus on, just tips that, like firsthand tips that you I mean, obviously I read the book, and I'm following the diet, but just to hear it, you know, from a real person does make a difference. Yeah.

Geoff Allix 16:28

Okay, thanks very much. I just want to apologize to listeners, because they're actually taking away all of the chairs, right now. Okay. But yeah, thank you very much for that. And, yeah, I'll be catching up with some more people later on. I'm here with Craig Hassed, who was a recent guest in the Living Well with

MS. Podcast, apart from being an OMS medical adviser. Craig is a medical doctor and coordinator of mindfulness programs at Monash University, one of the top academic institutions in Australia. Craig, I have a question for you that I've come across from time to time. What is the distinction between meditation and mindfulness? Because many people think it's the same thing. So what's the difference?

Craig Hassed 17:09

So rather than drawing a distinction between mindfulness and meditation, I'd rather having more of a sense of expanding the notion of what mindfulness means. So mindfulness is a form of meditation. So the stereotypical idea of a person sitting in a chair with their eyes closed, attention on the breath, or the body, so that they're not doing anything else, just practicing paying attention in a mindful way. So it's mindfulness meditation, or the formal practice of mindfulness. But mindfulness is not just that, it's what we do when we get out of the chair and back into our day to day life. So the informal practice of mindfulness is to be mindful while we're doing things. And that could include a day with plenty on and work and you know, things to do. And you're walking through a park. Well, to walk through the park mindfully, just to give yourself a mental break, and just to hear the birds and feel the breeze, when we're driving to drive mindfully, when we're eating, to taste our food and to eat mindfully. So it's really a way of life, not just a form of meditation. And then there are a whole range of psychotherapies that are based on mindfulness. So mindfulness based cognitive therapy would be the best known MBSR, Mindfulness Based Stress Reduction. But others will as well that like ACT or Acceptance Commitment Therapy, that doesn't emphasize the meditation side of things quite as much. But really emphasize a couple of the aspects of being mindful, like acceptance, that attitude of acceptance, being able to be okay with whatever's going on. Even if we'd rather things were different to accept the reality of what is in the present moment. Acceptance doesn't mean not responding or dealing with problems. But it just means accepting that that situation is the way it is. And commitment means to really engage with life to really have a commitment to living a commitment to being engaged with our life, rather than just going through the motions while we wish we're somewhere else or doing something else. And so another one's like Dialectical Behavior Therapy, again, are based on principles of mindfulness. But it's really taking elements of mindfulness and, I suppose repackaging them and presenting them in different ways that people can find very useful.

Geoff Allix 19:25

So the idea of mindfulness in your day to day life, if you're not concentrating on work, but you're just driving the car, or going for a walk, would you almost always do that in a minute, because that it doesn't count if you get to a destination and you don't remember getting there because it's the way you drive every week. That's not mindful, is it? I don't believe so. But we do try and be mindful, always yourself. You could go for a walk or drive or something like that.

Craig Hassed 19:56

Yeah, well, you know, if we're living on automatic pilot, it means the mind is almost constantly in a state of distraction. Now there's a term for that default mode, but the mind is a million miles away. And we're just going through the motions of life. Most of the time wishing things were different, wishing we were in the past or being anxious about the future, etc. So to be mindful means to really taste and enjoy our food when we're eating. It means to just enjoy the simple pleasures of life. But the mental rest some people think are mindfulness. It's such hard work. And if we're struggling with our mind and struggling

with our thoughts, and thinking that being mindful means trying to get rid of thoughts and then mindfulness becomes hard work. But if we realize, no, we just don't have to be constantly thinking, you know, when you're sitting down and doing some planning and preparation for something, and sit down and plan and prepare. But if you're between one complex job in your life, and another complex job, you might just be walking down a corridor at work, or walking through the park, between your car park and your office. It means just to give yourself some mental space to give yourself some mental rest. And just enjoy the moment for what it is but to cultivate a mindful state of mind to then take into the next complex thing you need to do take in a calm but attentive mind, to engage with all of the important things we need to do in our day to day life.

Geoff Allix 21:16

Okay, thank you very much for that. It's been a pleasure. So we're coming to the end of the day. And I just wanted to ask an attendee Pauline, how you found the day and how you found OMS in general?

Pauline 21:30

Well, today was inspirational as I expected it to be. Having become a very new member of the OMS family. I went on retreat two months ago. And it was a transformational week, I was a changed woman by the time I left and returned home. And today just provided more of that energy, of inspiration of hope, and of love this amazing OMS family.

Geoff Allix 21:59

We've come to the end of the day, and it's been a long, yet amazing one that I've managed to snag Professor George Jelinek, the founder of OMS, and Dr. Sandra Neate. George, I understand this may be your last appearance in the UK on behalf of OMS. Can you please tell us more about handing over the reins?

George Jelinek 22:18

Well, it's been a pretty deeply personal journey for me. Today, I've taken the last three to five years really trying to move the organization of OMS away from any kind of dependence on one individual, which in this case was me. And I always sensed that was somewhat unhealthy. And wouldn't stand the organization in good stead long term, that it needed more people to be representing the organization and needed a better mix of ideas that needed youth that needed enthusiasm. I've stepped down as head of the NEU in the last 12 months. And Sandra is now the head. The one thing I haven't stopped is my personal and really close connection with a whole range of people with MS. Some doing really well, some not so well. All of whom have completely different stories. But all of whom pretty much to the to the individual will say they're living their lives better than they were before. They found OMS and many of them are saying that they're living their lives better than they ever have. And for me, that's the culmination of all this work that I have an enormous sense that something really positive and useful and helpful has been done for people with MS. And for me that the integration was always wanting to see that people didn't suffer the way that my mother did with the illness. So I kind of feel like I've completed a bit of a circle and today closes that circle.

Geoff Allix 24:12

Thank you very much. I'd like to say that a lot of people just now have thanked you as well. And I'd like to personally thank you. I know that people listening to the podcast might think I thanked you quite recently. But in the real world that was about a year ago. So we actually there was a long delay between recording and going out so yeah, but yeah, I think I think everyone here would like to thank you for spreading that message that you discovered and not keeping it to yourself. Hi Sondra, and nice to meet you. So as the new head of the Neuroepidemiology unit at the University of Melbourne, what's in store for the work you're heading up there?

Sandra Neate 24:47

There is a continuation, a large part of our work is still continuing on with the HOLISM project and following the participants in the HOLISM project through to 2.5-5 years and ultimately beyond that. So there's a lot of work to still be done. Looking at the data from the participants in the HOLISM study into the future, we're also continuing on with our partners' work. And we're hoping to expand some of our qualitative research into talking to people with MS themselves about their experiences of lifestyle, modification etc.. And one of our big projects is focusing around the development of an online intervention. So what we call the MS Online Course, which is being principally developed by our PhD student Will Bevans as his project for his PhD with the support from the rest of the unit. And we're hoping that because the retreats are such time and resource intensive undertakings that somehow this, the magic of what happens at the retreats can be translated into an online course, for people that say that the reach is greater, and that many more people can experience the retreat type of experience without having to wait using the online modality. So that's an attempt of ours to move into the future. And so that's a big project that we're undertaking to do. We've got other other things on the go as well, but they're the main focuses of the NEU into the future.

Geoff Allix 26:21

Thank you very much. And thank you for coming around the world from Melbourne to Edinburgh to facilitate this, thank you. With that, I'm going to close out what's been a long, exhilarating and enlightening day with Professor Jelinek a dedicated team of OMS facilitators, and many members of the OMS community from around the world who've gathered here in Edinburgh to share their stories, and learn more about what's in their power that they can do in order to overcome MS. With that, I would like to thank you all for listening to this episode of living well with MS. Remember that there is a wealth of information at overcomingms.org including show notes, and an archive of all Living Well with MS episodes. Once again, that's overcomingms.org. There you can also find OMS friendly recipes and exercise tips. Connect with other OMSers in your local area through our OMS Circles program, and learn about the latest research going on in the MS world generally and related to OMS specifically, I encourage you to register on the site, and stay informed about the latest news and updates. I also encourage you to subscribe to this podcast, so you never miss an episode. And please feel free to share it with others who might find it a value. Let us know what you think about the podcast by leaving a review. And if you have ideas for future episodes, we'd love to hear from you. So please contact us via our website overcomingms.org. Thanks again for listening, and for joining me on this journey to Overcoming MS and living well with multiple sclerosis. I'm Geoff Allix And I'll see you next time

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