

S4E47 Transcript

Hello 2022, Hello OMS Handbook

Geoff Allix (1s):

Welcome to Living Well with MS, the podcast from Overcoming MS, the world's leading multiple sclerosis healthy lifestyle charity, celebrating its 10th year of serving the MS community. I'm your host, Geoff Allix. The goal of our organization and this podcast is to inform, support, and empower people with MS to lead full and happy lives. We're excited you could join us for this new episode. Make sure to check out this episode's show notes for more information and useful links. You can find these on our website at www.overcomingms.org/podcast or in whichever podcast platform you used to tune in to our program. If you enjoy the show, please spread the word about us on your social media channels or leave a review wherever you tune into our podcast.

Geoff Allix (47s):

Have questions or ideas to share? Email us at podcast@overcomingms.org, or you can reach out to me directly on Twitter @GeoffAllix. We'd love to hear from you. Finally, don't forget to subscribe to Living Well with MS on your favorite podcast platform so you never miss an episode. Now, let's meet our guest for this episode. More than 12 years since the first edition of Overcoming Multiple Sclerosis was published and six years the release of the second edition, Professor George Jelinek is back with the Overcoming Multiple Sclerosis Handbook: A Roadmap to Good Health. We are pleased to welcome back Professor George Jelinek, creator of the OMS program, and one of the three editors of this new highly anticipated book.

Geoff Allix (1m 32s):

We are also very pleased to welcome back to the podcast Associate Professor Sandra Neate, Head of the Neuroepidemiology Unit at the University of Melbourne, and another of the three editors of the new book. Welcome back, Professor George Jelinek and Associate Professor Sandra Neate. Could I call you George and Sandra?

George Jelinek (1m 54s):

Yes, of course, Geoff.

Sandra Neate (1m 55s):

Of course, yes.

Geoff Allix (1m 56s):

Welcome back to the podcast.

Sandra Neate (1m 57s):

Thank you.

George Jelinek (1m 58s):

Thank you.

Geoff Allix (1m 59s):

George is the founder of the neuroepidemiology or NEU unit at the School of Population and Global Health at the University of Melbourne. I will avoid saying that again. So, if I'm about to say it, I'm just going to say NEU. Okay?

George Jelinek (2m 20s):

It's quite alright.

Geoff Allix (2m 23s):

It's quite big news with the launch of a new book, and it's wonderful to have you back on the podcast. First and foremost, since we haven't had you as a guest for a while, can you fill us in on what you've been up to for the past couple of years?

George Jelinek (2m 38s):

Well, I think people may be aware that I retired in October 2019, which seems like a lifetime ago after all the events that have transpired since the start of 2020. I certainly planned a different retirement than I'm finding myself in with COVID, but I guess, one of the important projects and a really big project in that has been this book, which has really taken a couple of years to get together and get to the stage now where it's about to be released. I had had other plans. I'd had plans for travel.

Geoff Allix (3m 19s):

I was going to say were you planning on traveling? That probably didn't go too well.

George Jelinek (3m 24s):

No, that went out the window a little bit. We've done a few small trips whenever windows of opportunities have opened up, but Australia's had its particular response and it's been very hard to go anywhere really. The other thing, I guess, that I've enjoyed doing, and I was planning to do in retirement anyway, was do more of my writing and recording of music, which, as a young man, I used to do quite a bit of recording on a reel-to-reel type deck. Now, with digital stuff, a blank canvas opens up with all these techniques that you can use that I never had access to in the past.

George Jelinek (4m 8s):

I just laid down track after track, putting down little various instruments, then singing, putting the harmonies on, putting the drum track on, and so on. I've put probably seven or eight songs down during lockdown to the stage where they're ready to be released. I'm pretty happy with that little endeavor. It's been good fun.

Geoff Allix (4m 28s):

The future might be rockstar George Jelinek, previously known as your epidemiologist.

George Jelinek (4m 34s):

Well, I think a very small audience. Possibly family and close friends might be down.

Geoff Allix (4m 41s):

Could you tell us a bit about the new Overcoming Multiple Sclerosis Handbook, and how the project came together and came to fruition?

George Jelinek (4m 53s):

Well, listeners might not be aware that it is actually when Sandra and I were in the UK in the middle of 2019. You might recall we came over for the big Edinburgh event at that time. In fact, I think you interviewed me and Sandra at the end of that day. We went out to London after that and met with the board of trustees. One of the things that was high on their list of priorities was to look at updating the OMS book, whose second edition came out in 2016, and they thought it would be good to get a new offering out there for the OMS Community.

George Jelinek (5m 38s):

I was very resistant to the idea, really very resistant. I'd seen that last book as the last thing, the last big project I would do in writing, but Sandra and I talked about it. The more we talked about, the more we thought, "Actually, this is a really good opportunity, a very different opportunity than me writing a book. Why don't we get a whole range of contributors from across the OMS community worldwide to write it, not only their experiences but the skill and wisdom they've distilled over quite often long periods following the OMS program, adhering to the program, and get that into a big volume?"

George Jelinek (6m 27s):

Then it has a consistent theme and feel to it. Sandy and I were initially the editors of the book, and then we felt that we probably should broaden that a little. We asked Michelle O'Donoghue, who is a Harvard cardiologist who's been on the program for about 10 years and whom we met in Boston during the US tour back in 2016, to be a co-editor with us. That project really has taken a couple of years. We had to recruit that big group of people. There are 19

content chapters in the book, and every chapter in the book, bar a couple, is followed by a personal story from someone else from the OMS community.

George Jelinek (7m 16s):

It was a short story of their experience, usually trying to relate it to the particular content of that chapter. Then each chapter is also introduced by an inspirational quote from someone else in the OMS community. We've got around about 50 different OMS voices, all pitching together about the program, how to adapt, and how to adhere to it. What are the tips and traps around the program? What their experience might do in helping to illuminate the pathway for people with MS.

Geoff Allix (7m 54s):

Would people treat it as a companion guide? It's not a new edition, is it? It's a companion to the Overcoming MS main book.

George Jelinek (8m 4s):

Yes, they're two very different books. The last book was me, really my own voice, and trying very hard to put all the complex medical literature into lay language, to make a strong case for why the OMS program should be adopted. At times, looking back on it, I think I was more or less successful in that. Some of the science is a bit obscure and a bit hard to explain, but it seemed to hit a chord with a big portion of the OMS Community. A lot of people have adopted it but one of the constant bits of feedback we got was that it wasn't really all that clear on how best to adopt it.

George Jelinek (8m 53s):

This book really is that part of the jigsaw. As you said, it's a companion. It's not a research-based book so even though it's based on the program, which is, in itself, research-based, it's not a book that's full of references. It's much more full of the personal experience and wisdom that each of these people in our community has got. Many of these people are really well known to our community. People who've been OMS facilitators, people who appear on your podcast series, people who have done cooking demonstrations for OMS, people who range in profession from chefs to psychiatrists, to general practitioners, family medicine doctors, to psychologists, to astronomers.

George Jelinek (9m 49s):

We've got a whole range of people in there who speak from their experience. That's the flavor of it. That's the thing that we're really happy about that it's no longer this single voice, which is always problematic because it just really reflects my views and has become very ingrained. It's nice to see a whole lot of other people tell us their views and what they've found easy, what they've found hard, how best to get over some of those obstacles, and so on.

Geoff Allix (10m 25s):

Sandra, how'd you become involved as one of the principal editors of the new handbook?

Sandra Neate (10m 31s):

I was there at this meeting in 2019 that George referred to in London and I think when it became clear that George didn't want to rewrite the Overcoming Multiple Sclerosis book as we discussed we came up with this idea of something different. One of the main reasons we wanted to make it different was to, what we call future proof the book. Meaning that because the other book is full of hundreds of references, it really needs to be kept up to date. You need repeat additions so that the book doesn't become out of date. We planned this book to be future-proofed, meaning that it wasn't full of references to the medical literature.

Sandra Neate (11m 13s):

It was peoples', as George said, distilled wisdom. The idea was really germinated between the two of us and working at the university, I had a six-month sabbatical coming up in 2020 so this was my proposal as part of my sabbatical, to use three periods of two months that I had to, first of all, work together to recruit the authors and then edit the chapters that were coming in. We did it over the year really of 2020 and 2021 so seems like a long time ago now. That was my role, and it was a joint venture.

Sandra Neate (11m 56s):

George, obviously, had a lot of them within the community and he kept a track of all the authors and followed them up, et cetera. Then he, Michelle, and I edited all the chapters jointly, Michelle from over in the US with a newborn baby. She did as much as she possibly could and always added a voice of calm reason and a different perspective to the things that we thought. She had a new perspective to add to what we commonly think, which was a wonderful addition. That's the way it evolved and played out. It's been a really rewarding experience because we're very proud of what we've produced, but the people who were involved in it, of course, were very involved and very keen to see the end product.

Sandra Neate (12m 47s):

They definitely feel they have an enormous stake in it, and they do. That's a lovely feeling that it's a joint venture and a product that's been made by many people, like-minded people.

Geoff Allix (12m 59s):

Was it hard to manage people around the world? How did that work? They've added to the project, and you mentioned different voices like Michelle.

Sandra Neate (13m 12s):

Yes. Well, the three editors, we stayed apart from all the chapters, but really, we just sent out invitations saying, "Would you be interested in authoring the following chapter?" People were incredibly keen and helpful. There wasn't much that we needed to do to entice people to become involved. Yes, there were one or two people who were always a little bit late to meet their deadlines, but in general, everyone had their work back when was asked. It was an amazing thing. Really, they're all wonderful. It varied between the amount of editing that was required between chapters. Some required some work just to get them down to word limits and those sorts of things, but in general, it was a fairly easy task to get everyone to meet the chapters.

George Jelinek (13m 59s):

These are people who are incredibly well motivated to get this message out. As we were saying, many of them have been facilitators, many of them have done a lot of work for OMS, raise funds for OMS, and so on. Their hearts were most definitely in the right place and they're very keen to be involved enough. I've got to say, some of the chapters came back, they just blew our socks off. We were really quite amazed at the quality of the work, but also the depth of insight that these people had developed. Some of them have been on the program now for 10 to 15 years.

George Jelinek (14m 41s):

In that time, they may or may not have interacted terribly much with us, but they've clearly worked out their own ways of doing this. The chapter by Jack McNulty, for example, who I know has been on your podcast, but his chapter on food – I was just astounded at the quality of that one.

Sandra Neate (15m 6s):

I think the thing is too, some of the authors, being on the program for a long time, some of them have their own specialty, as in their medical specialty or their own professional specialty that, of course, has shaped their view of the program. They have perspectives that we didn't have, things that we'd never thought of because we've been doing the same work for a long time and it's progressed and evolved, but to hear a psychiatrist with MS talk about mental health is a really interesting novel thing because, although we know Keren Taylor very well and she's worked with us, to hear her written perspective on the whole thing was incredibly enlightening.

Sandra Neate (15m 47s):

George has mentioned a number of other chapters. Phil Startin, who wrote the progressive MS chapter, who's lived with progressive MS for years, had some amazing insights into progressive MS, and amazing facts, figures, attitudes, and ways to adapt the program to it. It's this new perspective and insights, professional and personal insights that were really useful.

Geoff Allix (16m 17s):

George, is there anything that you've come across in the past few years that maybe you've just been aware of or been involved in that has further supported the evidence for the efficacy of the OMS approach to lifestyle modification for people with MS?

George Jelinek (16m 40s):

Well, actually, Geoff, it astounds me the degree to which the ongoing research effort around the world into the lifestyle risk factors in MS has validated the program. I've actually been astonished when you see work come out from NARCOMS, for example, the North American Research Committee on MS, publishing in Neurology, the leading neurology journal pretty much in the world about their large data set of North Americans with MS and confirming the findings of our HOLISM study, that the higher quality diet, the less disability, the fewer relapses, the better quality of life, and so on.

George Jelinek (17m 31s):

Then that's equally supported by the UK MS Register, by the Dutch MS Society publication, and of course, our own HOLISM work. We keep publishing on that and we're up around 40 to 50 papers now in the mainstream major medical journals. They haven't contradicted really any of those things that came from a detailed systematic review of what was available originally at the end of the last century in the medical literature. That's where the program had its genesis.

George Jelinek (18m 11s):

The thing that 20 plus years on, the research continues to come out to support that and strengthen those pillars. I just find it amazing really to think back then there was enough there to be able to put a program like that together over 20 years ago, and then not to have it crumble, not perhaps a couple of big studies come out to say, "Look, there's nothing in the diet. The vitamin D connections are nonsense," or whatever. I've almost thought, "Well, one of those is going to come along and half expected it," and they haven't appeared in the literature.

George Jelinek (18m 54s):

I have to say, it's very reassuring for people who are on the program to know that. The science keeps getting better and better and there are better and better teams working on these larger and larger data sets from around the world. You can be reasonably confident if you're on the program, that the science is evolving to further support the OMS program.

Geoff Allix (19m 24s):

I think actually from my side, the neurologists are starting to come on board. Aaron Boster in the United States is a big proponent. He's been on the podcast a couple of times, and he's now involved in OMS, but just like my neurologists, five or six years ago, they were really unaware of lifestyle factors. Now, most of them have, at least, an awareness. Really, it's not rocket science in many ways - eat healthily, do some exercise, look after your mental health. This isn't a crazy thing that we're talking about.

Geoff Allix (20m 6s):

We still, technically in the UK, have dairy as a food group. You have to say to people on the whole like "Actually, no animal on earth has breast milk as an adult." They start thinking, "Yes, maybe it isn't that normal."

George Jelinek (20m 24s):

Yes, especially in other species.

Geoff Allix (20m 29s):

Yes, that's very weird indeed. Then you think, "Actually, yes, it isn't an odd thing you're doing. It's actually just a very healthy lifestyle." Actually, I've come across people with other autoimmune conditions like rheumatoid arthritis, Parkinson's, cancer, who've all had similar recommendations, not identical, but very, very similar. You're thinking if there are organizations in those areas, they're all saying, "Eat a largely plant-based whole food diet, do more exercise, and look after your mental health,"

Geoff Allix (21m 10s):
then there's definitely something in this too.

George Jelinek (21m 14s):
Yes, and I guess the other side of that is that you have to continually remind yourself that it's not a program that comes with any risk. It's a risk-free program. Even if the literature had been published to show that it wasn't particularly effective in MS, at the very least, you can be confident that you wouldn't get any of the other conditions like cardiovascular disease to the same extent. In an indirect sense, even if something did suggest it wasn't that helpful in MS, you know you're helping indirectly the course of MS by adopting that really healthy lifestyle.

Geoff Allix (21m 56s):
Yes. That's exactly what my neurologist said. In the first meeting, I presented the book and said, "What do you think?" He referred to it as the Jelinek method, I think he called it. He said, "Well, there's no proof that will do anything for MS," which I think they have to say really. They're in the national health service. They can't go off message. I think probably they might get into legal issues. There isn't proof. It's not a proof thing, is it? In fact, there are no proofs in medicine. I think you need mathematics to prove.

George Jelinek (22m 37s):
That's another podcast, isn't it? Let's discuss the concept of proof in medicine and I'll tell you, that's a very slippery topic.

Geoff Allix (22m 46s):
He said, "But it's going to lessen your risk of heart disease, cancer." He went through a whole long list of things so he said, "Ultimately, if you're happy to do it, then I would absolutely recommend you do it because it will just improve your health."

Sandra Neate (23m 2s):
I would be very happy if one day, they could make the leap and stop saying, there is no proof and say, "Look, there is a lot of evidence to support this lifestyle in many illnesses and go for it."

George Jelinek (23m 16s):
Yes, and we're working on those as a charity. I think that's one of the next big challenges for the charity now that it's got a new board chair. I think a key aim is to work out a strategy for approaching the profession in a way that will keep them on side so that they feel comfortable recommending this kind of lifestyle. Actually, one of the things about this book is that it's the perfect thing for a doctor to hand one of their patients with MS because it just lays out the prescription so beautifully in such an easy way to follow that would save them an enormous amount of work trying to go through the explanation about the diet and so on.

George Jelinek (24m 8s):
It's all there. It's just such a handy little companion to adopting something like this in life.

Sandra Neate (24m 14s):
Would you recommend it more for newly diagnosed or is there a particular audience in mind?

George Jelinek (24m 22s):
I think it's anyone at any stage of the illness. We've been very deliberate in not just discussing the seven pillars of the program, but in broadening that very significantly. For instance, Rebecca Hoover from Minnesota talks about the issues around work discrimination for people with disability, what kind of options are open to them. Greg Herndon from Northern Ireland talks about disclosure, how, and when, and who to tell the diagnosis to. Rachael Hunter from Swansea talking about resilience, which applies, of course, to any stage of the illness.

George Jelinek (25m 9s):

As Sandra said, Phil Startin got some amazing insights about the journey that people who have progressive forms of the disease and find themselves undertaking. We're very keen that this is a very inclusive, much broader-based book that deals with many of those issues that people might only be becoming aware of much later in the disease's course.

Sandra Neate (25m 33s):

Also, issues that are actually extremely common, such as pregnancy. The majority of people with MS are young women and rarely do they get the opportunity to talk about pregnancy, childbirth, and the neonatal period managing newborn babies and how to deal with families and relatives, and things like that. Things that are actually very common, but not commonly discussed. We hope that by broadening out from the seven pillars, there's some really useful information there, no matter what stage of the journey they're on and whether that's newly diagnosed, 25 years into the illness, or longer.

George Jelinek (26m 16s):

Sandra, from an NEU perspective, how does this new book add to the ways in which we're trying to advance lifestyle modification therapy for people with MS?

Sandra Neate (26m 33s):

Well, it's a highly valued publication and, in any research, the publication is what counts. George and me, because of our involvement in the book, we were awarded the Melbourne School of Population Global Health Engagement Award for the contribution that this made towards engagement with our MS community and, in their mind, with our research subjects from an academic perspective, it's highly valued that researchers engage with the participants in their research. They involve them at all stages of research, before research, during research, after research, report back to them.

Sandra Neate (27m 18s):

They love the way The NEU engages with the MS Community. They highly value that so that in itself is a really important contribution that the book has made to the unit. We are a very small unit. There's really, at the moment, only five of us and a couple of students, so a major publication like this is extremely important to the unit. Really, although the rest of the team weren't directly involved, all the subject matter is what we're involved with on a day-to-day basis in our research and the HOLISM study and all those sorts of things.

Sandra Neate (28m 0s):

It's a very important publication for the university. The university highly regards it, and the NEU has benefited from that.

George Jelinek (28m 10s):

To either of you, when is the book out and how do we get hold of it?

George Jelinek (28m 16s):

First of February 2022, so we're there now and in the year that it's being released. We've only got to wait another few more weeks. It's been really, simultaneously, in the UK, US, and Australasia. Really, as I say, in all good bookstores and all book websites. You can get it on Amazon, on Booktopia, all the usual places, and it'll be freely available soon. It's only available for pre-order at the moment.

Sandra Neate (28m 53s):

I think, actually, from when this podcast airs, I'd say it's out now. We're recording this a couple of weeks early.

Geoff Allix (29m 08s):

Sandra, are there any final thoughts or words of encouragement for the OMS community?

Geoff Allix (29m 14s):

Yes, always. We're working hard on lots of interesting projects. Did you mean from our research, from our unit's perspective?

Geoff Allix (29m 19s):

Yes. Just for the OMS community, is there anything upcoming? Is there anything that you think they should be doing? Just a final thought to the community.

Sandra Neate (29m 34s):

Well, we're engaging more and more with other collaborators around the world to enhance our research, and all the things that they're all doing, and to understand further the benefits of the OMS program. We're working on an online course that will be there in the future for their use once we've tested that and made sure that it's working well and that it's effective in achieving what we hope it will achieve. That hopefully will be released around another year or so. It's a very slow process, all these things, but everything that we're doing is there to understand further and hopefully support all the efforts the OMS community is making to manage their own health.

Sandra Neate (30m 22s):

The more work we do, the more we understand that people who take control of their health, who feel the empowerment to make changes in their lives have improved mental and physical outcomes so there's no downside to this. We're just hoping to find more and more evidence that this is the case for the people in the program.

Geoff Allix (30m 52s):

George, one final question. Overcoming MS is celebrating its 10th anniversary this year in 2022. What is your anniversary wish for OMS?

George Jelinek (31m 03s):

Well, I think for me, what I always hoped was that we would ultimately reach the mainstream professional community so that if a person is diagnosed with MS, then, in the same conversation as the diagnosis, it offered a suite of things that they can do for themselves that are evidence-based and that they can adopt with confidence that their neurology team, their general practitioner, their MS nurse, that professional community is right behind them in the things they're doing for their own health. Twenty years ago, that seemed like a bit of a long, distant goal. It's still, possibly, some way off, but that's what I hope the OMS charity achieves over its next 10 years.

Geoff Allix (32m 0s):

Thank you very much, George and Sandra, for joining us on this episode to announce the publication of the Overcoming Multiple Sclerosis Handbook: A Roadmap to Good Health. We encourage everyone listening to read the book. Information on how to get it is available in the show notes. As George mentioned, it's available through all good booksellers. Thank you both for everything that you do to advance the mission of OMS and the benefits of lifestyle modification for all people with MS. I hope you both have a very happy 2022.

Sandra Neate (32m 42s):

Thanks, Geoff. Thank you. Thanks for having us. It's been a pleasure.

George Jelinek (32m 42s):

Thank a lot, Geoff. Great to talk to you again.

Geoff Allix (32m 43s):

Thank you. Thank you for listening to this episode of Living Well with MS.

Geoff Allix (33m 41s):

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