

S3E44 Transcript

Empowering Advocacy

Geoff Allix (1s):

Welcome to Living Well with MS, the podcast from Overcoming MS for people with multiple sclerosis interested in making healthy lifestyle choices. I'm your host Geoff Allix. Thank you for joining us for this new episode. I hope it makes you feel more informed and inspired about living a full life with MS. Don't forget to 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. That's the kind of viral effect we can all smile about. Finally, don't forget to subscribe to the show on your favorite podcast platform so you never miss an episode.

Geoff Allix (44s):

Now without further ado on with the show. Today's podcast is different to every other one that we've had so far in that we have two guests, and we're going to discuss advocacy. And joining me today are Alison Marwick and Helen Rees Leahy. And I'm going to get Alison and Helen to introduce themselves. You may be familiar with Helen; she's already been a podcast guest. I believe it's season two, episode 30 off the top of my head. But there's a podcast about PPMS with Helen, but to start off with, would you like to, well, firstly, welcome and could you introduce yourself, Alison or Allie?

Alison Marwick (1m 31s):

Thanks, Geoff. Yeah, delighted to be here on this podcast today and talking a bit about advocacy. So, my name's Alison or Allie Marwick, I have relapsing remitting multiple sclerosis, and although I was formally diagnosed 10 years ago in September 2011, I had my first episode in 2004. So, I've been living with the disease for the past 17 years. I'm fortunate in that I found OMS within about a month of diagnosis, which was great because during that period, I was probably depressed having gone through that grief cycle of being diagnosed and not really knowing what to do, but I was physically well, I was mentally well, but I had this, what I felt was, you know, a hideous disease and that my life was over.

Alison Marwick (2m 36s):

So, finding Overcoming MS within a month was hugely empowering and gave me so much hope. And it enabled me to really take steps in my life that I had been afraid to before. I had been told in 2004 that I probably had MS, or it was highly likely, I think they phrased it, but I pretended that it wasn't there. And I just was living in denial and in fear. And what OMS gave me was that ability to not be fearful anymore, to have hope that I was able to manage my life and that it wasn't over. And I could do all the things that I wanted to do by following the program and have great health outcomes.

Alison Marwick (3m 19s):

So that's, you know, that's kind of my story in terms of OMS and how I found it. And I, ever since then, I've been passionate in wanting to support the organization, support other people who are following the program or looking at or interested in following the program. So, I've been an ambassador for Surrey, which is where I lived for the last three years, which has been hugely rewarding. And, you know, we've got an active circle here, which has been great fun and, you know, helping and working with others who are following the program.

Geoff Allix (3m 52s):

Excellent. So also joining is Helen Rees Leahy as mentioned. So, Helen, could we have a quick intro from you?

Helen Rees Leahy (3m 59s):

Hi, Geoff. Hi, Allie. Hi, everybody. Thank you very much, Geoff, for asking both of us to come on to talk about advocacy today. I'm Helen, Helen Rees Leahy. I was diagnosed with primary progressive MS in 1997. So, I've been living with MS now for nearly 25 years. And as I had a diagnosis of primary progressive from the outset, I have had that course of increasing progression of my illness. I discovered OMS a long time ago, actually. I mean, I think it was

something like 2008 when Professor George Jelinek published one of his very early books outlining the backbone of the OMS program.

Helen Rees Leahy (4m 46s):

And I seized upon that. I have never been eligible for a disease modifying therapy under the UK NHS system. So, I've always been managing my MS through my own actions and agency, and like Allie discovering the Overcoming MS Program was a tremendous support for me and indeed it supported me throughout my time, my life with MS and continues to do so. So, I think I'm very touched by what Allie says about, you know, overcoming fear and anxiety. And that's something I'd like to come back to. I think in the course of this conversation, the importance of the program, not only in enabling us to lead very healthy lives, as healthy as we possibly can with this condition, but also the emotional, the mental, the psychological support that it gives us in terms of becoming less fearful, becoming less anxious about our conditions.

Helen Rees Leahy (5m 51s):

And that's very much, I think, at the core of the advocacy initiative, the ways in which we can really realize the goal of empowerment, empowerment for ourselves and for each other as a community of people living with MS, following the OMS program.

Geoff Allix (6m 13s):

Can we start out just as a basic, what is advocacy? To start off with. I think a lot of people won't have heard the term too much. So, could we just define advocacy and the types of advocacy as well? Who wants to take this one out?

Helen Rees Leahy (6m 29s):

I'll kickoff, but Allie, I know will come in there as well. I mean, that's right. It's perhaps a rather abstract word. We relate it as I was suggesting a second ago, very much to our strategic goal of empowerment within OMS and really what it is, is making the case for the OMS program. So, if you think about it this way, I think as an organization, we're very good with information to go into the website. There's a massive amount of information about the program, how to implement it. You know, your questions are answered there, but we know that living with MS is challenging and convincing other people of the benefits of following a program like Overcoming MS.

Helen Rees Leahy (7m 16s):

It can also be quite challenging. Maybe those, it could be family, friends, it could be your healthcare professional. They don't always understand the program, they don't always see the benefits that we ourselves perceive from it. So, it's making a persuasive argument and it's finding the words and the confidence to make the case for following the program. Sometimes in perhaps what might be quite difficult or challenging situations, you know, where you need to be persuasive. It's beyond information. It's a process of a persuasion. And I say, we can do it for ourselves. We can also do it for each other as well.

Geoff Allix (7m 58s):

And Allie, do you have anything to add to that?

Alison Marwick (7m 60s):

Yeah, I would agree with that. I think, you know, there are two keywords there that Helen references: empower and confidence. You know, giving people the tools and the techniques and the confidence to be able to talk about their own diagnosis, talk about their own choice to follow the program and the benefits that that's shown. We know from the community engagement survey data that was, you know, we're currently trawling through as an organization, that a lot of people struggle with talking to healthcare providers, talking to their friends and family, but having your friends and family on side is a huge support network.

Alison Marwick (8m 43s):

It's really important. And we knew that you, having the confidence and the ability to be able to articulate what it is that you're doing and why, and not have to be defensive and constantly, you know, people going, oh, go on just to have a wee bit cheese or whatever. And so, it's about, we want to enable people to have that confidence, to have

that ability, to have those conversations in any environment, whether it's friends, families, healthcare professionals, work, those sorts of areas that we'd recognize, but we maybe need to provide a bit, a few more tools, techniques, and support in order to be able to do that.

Geoff Allix (9m 20s):

Absolutely. I think I bet anyone who's got MS and following OMS, I think will be familiar with this. I think, I consider myself very lucky in that my neurologist is very supportive, but I've certainly had many stories of-- probably isn't fair to say, old school neurologists, maybe more traditional, if you like, who really are very much of the opinion, you take the medication and you live life. Literally, I think the phrase did come up like, you know, you've got MS, you don't want to make things any worse and just enjoy life while you can.

Geoff Allix (10m 1s):

And it was some really cutting remark like this I've heard, but actually when you look at some of the top neurologists, you know, some really leading neurologists, they are almost entirely of the opinion that lifestyle is a factor and living a healthy life will have an effect on your MS prognosis. So there is definitely, if you've got an up-to-date, if you like, neurologist, they seem to be very pro the OMS approach, but yeah, there are still some more traditionalist and equally person to person as well, because I think all of us will have come across someone who I think you said, why not just have a little bit of cheese, and that is absolutely the case with some people.

Geoff Allix (10m 49s):

Again, I feel very fortunate. My family and friends are generally very supportive, but it still happened, you know, a little bit won't hurt sort of argument. So how is advocacy particularly important to the OMS community then? And to the broader MS Community?

Helen Rees Leahy (11m 14s):

For me, that's all about individual and collective agency. So, when any of us has a diagnosis of a condition like MS, as Allie was saying, you know, there can be very devastating concerns. And, you know, people of course react in very different ways, but it's, you know, it's a profound change in anybody's life. And in fact, it can be a very traumatic period for people, but what the OMS program does not only, you know, is provide a toolkit to enable us to lead a healthy life.

Helen Rees Leahy (11m 56s):

It's also a means of covering our own personal agency of taking control, of feeling that something that we can do and in time, you know, perceiving the tangible benefits of following the program. So, for me, it's that process of taking control, which I think is so incredibly powerful. That is why we believe, of course, the Overcoming MS Program is so valuable in all of our lives and combined elements of it is a kind of more than the sum of the parts. So, I think we know this as individuals, but perhaps as a community, we haven't been quite as clear in articulating that within the MS space more generally.

Helen Rees Leahy (12m 46s):

So, I think it's about within the OMS community, becoming more empowered, connecting with each other. And as I say, becoming a stronger voice for the program within the MS space. So, as you say, Geoff, with a healthcare professional, who's a little bit skeptical, with a family member who, you know, is perhaps questioning why somebody with OMS needs to have time and space for meditation or stress reduction, why family food might need to change. So, I think it's about increasing confidence, increasing empowerment, and doing this collectively. We're not expecting, you know, sort of magic wand that any one individual can do this by themselves.

Helen Rees Leahy (13m 30s):

So, it's one of the ways in which we want to become more connected as a community as well.

Geoff Allix (13m 40s):

And how can you advocate by using your own experiences? What approaches have you had for that? Could ask that to Allie if--

Alison Marwick (13m 53s):

Yeah. Yeah. So, I think a lot of OMSers are naturally advocates because, and you've had many of them here doing podcasts and talking passionately about how following the program has transformed their lives. And as Helen said, not just from a physical perspective, but from a mental perspective, and how they feel about themselves and their own empowerment. So, we can all be advocates just by, you know, talking about our own experiences. And Helen, I'm sure you experienced this as well, but when I meet new people and you're having food in a restaurant or something, and everyone was like, "Oh, what can you eat?"

Alison Marwick (14m 37s):

Why do you do that? Like, well, this is why, and this is, I've lived with this disease for, well, had a diagnosis for 10 years. I've followed this program for 10 years and I am in remission and everyone's like, wow. And they get it, you know, some people want to know more. Some people are like, oh, difficult subject, don't want to talk anymore. But I think everybody can be an advocate. We're not, what we're not saying here is everyone has to be. But I think by default, just by having conversations with your family and with your friends and by living your life, people will see that there's something there that you can, that you've got the confidence, you've got the ability and the, you know, you're managing your disease.

Alison Marwick (15m 22s):

Helen, I don't know if you want to add to that.

Helen Rees Leahy (15m 26s):

Yeah. I think you're absolutely right, Allie and I think the only thing I would add to that is for me, it's, as you say, our own kind of personal stories can be very powerful. And there's an idea which is becoming increasingly accepted and talked about within healthcare systems here in the UK, but also in other parts of the world as well. And this is the idea of experts by experience. It's the idea of the so-called patients being a kind of co-creator of their own kind of treatment plan and parts and acknowledging that alongside the medical model of medical knowledge and research, there are other forms of insight, knowledge, and understanding, which come from the lived experience of an individual and a group of individuals.

Helen Rees Leahy (16m 21s):

And it's particularly true with kind of chronic conditions, such as MS. For me, it's more than just our own individual stories. It's actually reflecting on what we've learned, what we learned from those experiences and actually looking for what we have in common, because we know as we've said in this conversation already so far, each of us has a very distinctive experience of MS. And sometimes, you know, your experience is nothing like my experience. Let's put those differences to one side and focus more on what we have in common, what we learn, what we can learn jointly.

Helen Rees Leahy (17m 9s):

And I should say, acknowledging both our vulnerability, but also our agency, our vulnerability I think, is what we get from MS. And I think our agency is what we get from OMS, from Overcoming MS.

Geoff Allix (17m 20s):

And just as an aside, I mean, I find a lot of people who follow OMS and certainly myself, people always say, you look really healthy, and you look really well. And I've heard that from a lot of OMSers that people are always commenting. How well we look, and I said, I always say, well, yeah, apart from the obvious then yeah, I do actually feel, I think it does actually my sort of ex-- lived experiences that I am definitely healthier apart from the fact of MS. And that my healthcare providers are on board with that, and they said, yeah, I noticed that you're living a really healthy life.

Geoff Allix (18m 0s):

You're doing exercise, you're eating a whole food diet, which is good, stress reduction, good. All those things are good things. It's not a, we're not doing some sort of really weird, out there, sort of unusual remedy. These are well founded, healthy things to do.

Helen Rees Leahy (18m 21s):

Well. I think that's exactly right, Geoff. And if you had diabetes or a particular heart condition, much of the kind of advice that we follow in OMS would be recommended to you by your healthcare professionals, without any question at all. It's orthodox, it's standard practice. As you said, a few minutes ago, unfortunately, lifestyle management, let alone Overcoming MS isn't yet a kind of standard prescription for people with MS. But you're absolutely right, with-- and you also said something interesting a moment ago about, well, you've got MS so why not enjoy life, which kind of implies that somehow following the OMS program, you know, robs you of enjoyment, well far from it.

Helen Rees Leahy (19m 7s):

You know, I think instead of thinking of it as a sort of rule space, sort of diktat, which, you know, is somehow a constraint. In fact, of course, it's a fa-- as you say, it's a foundation to be free and to lead a good life, a healthy life. And of course, to lead the best lives we can with MS.

Geoff Allix (19m 35s):

And Allie, have you got a point as well? On that?

Alison Marwick (19m 37s):

Yeah. I would add to that, just go back to your comment, Geoff, about people tending to comment that OMSers look well, I think the key thing though is that OMSers know that there are so many hidden aspects of MS. And so, you may look brilliant, you may-- you know, your skin, your hair, everything might be great, but you could be in a lot of pain or, you know, suffering from one of the many things that we know that are hidden to the wider world. So that, I guess, you know, one of the things that we do bring to bear in these kinds of conversations is that yes, we know that the health, the lifestyle and the-- is great.

Alison Marwick (20m 21s):

And people comment that physically, we look like what they can see, we look well. But actually, those of us who live with the disease know that there's lots of hidden things there as well. So, we're not, we're not dismissing that, but acknowledging it, and you're working on, you know, helping people in, you know, who are struggling with some of those areas as well. So, there's, it's not, we're not all running marathons and all that kind of stuff. It's about empowering people wherever they are with their disease, and you know, where they are physically and mentally, even if everybody thinks we're all fine.

Geoff Allix (21m 5s):

Yeah. We're like swans. We look great on the surface, but an awful lot of work underneath.

Alison Marwick (21m 8s):

Absolutely. Absolutely. But, and to Helen's point, you know, I don't, I agree. I don't think that following OMS is a burden. I don't know if somebody told me I could eat meat tomorrow, I'm not sure that I would. I'm, you know, I have-- my life is much more enriched. I've had more confidence, I think, as a person to be able to do things, but I never thought prior to diagnosis that I would do, I guess I've taken life by the horns a little bit more than I would have done before. And certainly, living those years between 2004/5 and 2011. I lived in fear just waiting for the next relapse to happen and made some lifestyle or life decisions that I've completely reversed since following OMS, because I'm not afraid anymore.

Alison Marwick (22m 2s):

And I think that's, I think, you know, giving people their hope back is such an important thing with OMS.

Geoff Allix (22m 13s):

And so, we talked about advocacy a lot, now on to the OMS advocacy group. So, what is the advocacy group and why is it important to have this group?

Helen Rees Leahy (22m 26s):

So, we created the advocacy group at the start of this year, starting 2021. And the importance of it is precisely that it's the goal of empowerment needs to start at home, i.e., within the OMS community. So, with all this discussion about advocacy, we're very clear about this guiding principle, that it must be a kind of community-led initiative. So, from the outset, we wanted to have the voices of OMS as around the table, helping us to start the conversation. And I would certainly want to emphasize that we're still very much at the beginning of this work, which is why it's so great to have this conversation today because we hope it might be a spur for more people to join in the conversation.

Helen Rees Leahy (23m 13s):

So, so far, the advocacy group has met, I think, four or five times. It's a small group of OMSers. And we've really been just trying to kind of unpack this, just what we'll be doing today. Really just what this word advocacy means and what might it mean in practice with OMS. So there, the advocacy group is important because it's an initiative which is being led by OMSers. And as I say, we're certainly not complete as a group with small gathering so far. So, if anybody's listening to this podcast today and would like to become more involved, either by suggesting they might want to join the group, we meet every couple of months on Zoom and, or contributing to our advocacy thinking in any other way.

Helen Rees Leahy (24m 1s):

If I may just say, Geoff, as soon as this podcast goes live, also going live will be a [new advocacy page on the Overcoming MS website](#). So, if you're on the website and you type in advocacy, or if you're in Google and you type in Overcoming MS advocacy, you'll land on that page. It will give a bit more information about where we are so far, and they'll also be a kind of contact info there. So, you'll be able to get in touch with us if you'd like to be more involved in it, to find out more about what we're doing. And we'd really, really welcome that. As I say, we think sort of empowerment has to start within OMS and we're really determined that we sort of put that principle into practice.

Alison Marwick (24m 48s):

Yeah. And just to add to that, Helen, I think is key for anyone that's listening, that we would love people to join the group because we do need more members, but also if you feel that joining the group is too much of a commitment and you don't, you know, you're not comfortable with that, but you want to share something, share an experience. You know, for OMS, the advocacy model we're seeing as being in three parts of self-advocacy being able to talk about it yourself, to your friends and family, and peers. So, talk to other OMSers or OMS or collectively as an organization, you know, to healthcare providers, if you have stories, or if you've got something that you want to share with us, you don't have to join the group.

Alison Marwick (25m 36s):

But we're keen to hear, we're, as we mentioned earlier, we're looking at the community engagement survey that so many people responded to over the summer, which is great. And there's a huge amount of data in that, around how people feel empowered or not, some of the challenges that they have. And, you know, so there's some decent information that we can use that, but if, you know, if you haven't shared with us some of your experiences and you feel that, you know, it's something that the organization needs to be aware of because it could help other people, then, you know, the call to action is for those as well as, you know, other individuals, to join the group.

Geoff Allix (26m 20s):

And if someone's not comfortable with joining a group, whether they don't have time or they're just, they're not comfortable with sharing, are there resources for people to help them with their advocacy journey?

Helen Rees Leahy (26m 38s):

Definitely. Well, as Allie said, definitely there will be. What we did want to do is sort of go off and design those resources by ourselves without talking with our fellow OMSers. So that's exactly what we're planning to do. And as Allie says, people can contribute to that process in all sorts of ways. So, what we're aiming to do, and it will be something which I think you'll be able to see sometime in 2022, we want to take it carefully. We're developing resources, which will specifically be there to support people in as with talking, making the case, perhaps giving them some tools and tips for perhaps quite tricky conversations.

Helen Rees Leahy (27m 25s):

When, you know, you're talking to somebody who's a little bit skeptical or resistant to your own kind of commitment to Overcoming MS. So, for example, some of the resources we might have might be frequently asked questions, we might play out some different scenarios, you know, how to cope with challenging or tricky conversations. We're having conversation starters, how do you kind of begin to talk to different people, family, friends, colleagues, healthcare professionals, about this? If you're going to see a healthcare professional, be it your family doctor, or hospital neurologist, or MS Nurse, for example, how might you prepare for that encounter?

Helen Rees Leahy (28m 11s):

How might you prepare for that meeting? How might you begin to talk about Overcoming MS with a healthcare professional? And I think that can be quite a challenging meeting in some respects because we know that our expertise is the expertise of lived experience. And as you were saying a few minutes ago, that's neither better nor worse, but it's very different from sort of the medical model for medical expertise. So, we need to be clear about the insight and understanding that we bring to the conversation based on our lived experience and how that can communicate and become a conversation with a healthcare professional.

Helen Rees Leahy (28m 55s):

So, we're thinking about these kinds of resources and that's sort of really a first step. So yeah, that's where we're thinking at the moment. But as Allie says, where we're really beginning is also a process of information gathering. So, looking really closely at the community engagement survey data, which is fascinating. And we might just take this moment to thank anybody and everybody who's listening, who participated in the survey because really, you know, your responses are providing really for the first time, I think for Overcoming MS, you know, statistically robust sample of data and findings, which are telling us so much already, and we've really want to root this initiative in that lived experience of the OMS community.

Geoff Allix (29m 55s):

And could I ask, what do you think success would look like? How do you measure success, or what do you expect to be a successful outcome of the advocacy group in OMS?

Helen Rees Leahy (30m 14s):

Do you want to have a go with that Allie?

Alison Marwick (30m 15s):

Yeah. So, success, so we're going to measure success in a number of different ways. And I think we're going to, you know, we need to look to see if there's the global success in OMS being everywhere, but that's going to be quite a way off. So, let's look at it. The community engagement survey is going to be done on an annual basis. And so, we will be using the empowerment questions that are part of that to see whether or not we've shifted the dial on how empowered people feel and having control, how confident they are about talking to their healthcare providers, how supportive family and friends are. So, we're going to use that as a mechanism to be able to measure, but that's going to be another year before we do that.

Alison Marwick (30m 59s):

So obviously we're not going to just sit back and wait to see what the results are, I think other success factors are going to be about how many people engage with this process that want to get involved. And we're going to look at success with, you know, some of the material that's going to be created in terms of, as Helen said, talking to healthcare providers, you're preparing for those kinds of conversations. How many of those items get downloaded from the website? What the kind of conversations are across the forum and the website, and looking at it, generally you know, how many more people are finding it, you know, finding the confidence and the empowerment.

Alison Marwick (31m 48s):

So, we've not put together specific, eh, KPIs, success factors at the moment, not wanting to be too corporate about it, but, you know, because we are right at the very beginning. But we are, you know, we're looking at well, what do

we want, what is success going to be in the next six, 12 months before we move into, you know, really accelerating us further down the line?

Geoff Allix (32m 12s):

Helen, do you have anything to add to that?

Helen Rees Leahy (32m 16s):

No, I think Allie outlined that very well. Again, if you're listening to this and you think, okay, I know something that will be a good measure of success. Let us know. You know, as I say, we really want this to be very much informed by anybody and everybody within the OMS community. So as Allie says, I'm reluctant to pin things down too hard and fast too quickly.

Geoff Allix (32m 42s):

So, with that, I'd like to thank you very much for joining us on the podcast and encourage everyone to have a look at the [OMS advocacy page](#) and wish you every success for the OMS advocacy group. So, thank you very much for joining us, Helen and Allie.

Helen Rees Leahy (33m 1s):

Thanks a lot, Geoff.

Alison Marwick (33m 3s):

Thanks, Geoff.

Geoff Allix (33m 4s):

And thank you for giving us this chance to wave the advocacy flag. Thank you.

Alison Marwick (33m 13s):

Yes, thanks very much.

Geoff Allix (33m 14s):

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Geoff Allix (34m 1s):

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