

S3E40b Transcript

Coffee Break #21: Julie Pankhurst

Geoff Allix (1s):

Welcome to Living Well with MS Coffee Break, a part of the Overcoming MS Podcast family, made for people with multiple sclerosis interested in making healthy lifestyle choices. Today, you'll meet someone living with MS from our global Overcoming MS community. Our guest will share their personal perspective on the positive and practical lifestyle changes they have made, which have helped them lead a fuller life. You can check out our show notes for more information and useful links. You can find these on our website at www.OvercomingMS.org/podcast. If you enjoy the show, please spread the word about us on your social media channels. Finally, don't forget to subscribe to the show on your favorite podcast platform so you never miss an episode.

Geoff Allix (44s):

So, get your favorite drink ready and let's meet our guest. Welcome to Living Well with MS Coffee Break #21, where we are pleased to welcome Julie Pankhurst as our guest. As always, your comments and suggestions are welcome by emailing podcast@OvercomingMS.org. We hope you enjoy this episode's conversation with Julie, coming to you straight from England. Julie, welcome to Living Well with MS Coffee Break, and we are very pleased to have you on our program. The purpose of this series is to better get to know some of the diverse members of our community from around the world. And today you're in a hot seat. So, could you tell us a little bit about your day-to-day life?

Julie Pankhurst (1m 27s):

Hi, Geoff. Well, my day-to-day life is never the same every day. Going back, I guess I'm 54. I live in North London in England. I'm currently on holiday down, just very close to you in Devon overlooking the North Atlantic Sea, so it's wonderful here. It's a beautiful sunny day. My day-to-day life, it's really difficult to put into words what my day-to-day life is because I'm in a lucky position that it can be different. Every single day is different.

Geoff Allix (2m 7s):

When were you diagnosed with MS and how did you initially deal with your diagnosis?

Julie Pankhurst (2m 16s):

So, I was diagnosed with MS in 2019, Valentine's Day 2019 actually, and before then in January, I was out. I just got walking quite a bit with my husband and I started getting-- I started having to hang onto my husband when we were walking because my balance wasn't too good. My legs would just ache quite a bit. And in January of 2019 I was working in London, I tripped over twice, blamed it on the curbs, which was normal.

Julie Pankhurst (3m 5s):

And then later that same day, I started getting what I now know is foot drop. So, I was walking on, and my leg was dragging behind, my left leg was dragging behind it and <inaudible> and my husband noticed it. And when I went home, said what the hell is happening? That was not normal. What's going on? So, I looked at Doctor Google and Doctor Google said MS and I went, huh, that's why I don't look at Google because it tells you silly things like that. So then, later in February that year, I decided to bite the bullet and have a health, full health scan--

Geoff Allix (3m 54s):

Yeah, a full check-up. Yeah.

Julie Pankhurst (3m 57s):

Yeah, that will do, thank you. I do suffer from a brain fog a lot and, anyways, you have to correct me quite a lot. So, yeah, I went for a full medical, that was what I was trying to say. And paid for this and I've been putting off having one for years and years, because I knew that I wouldn't be able to run on a running machine. I would fall off it or I'd just stumble, or it just filled me with dread. But my husband was going for one, said come on you should go for one too. And I thought, yeah, what the hell because I knew I've been to the doctors over the years, once a year with various things, I knew something wasn't right in my head.

Julie Pankhurst (4m 37s):

A lot of people say that, but I knew that I was having brain fog regularly. I would stumble over words. I couldn't remember words. I'd be forgetful. And the doctor said it's-- You know, he did a check for me, you know, a normal sort of Alzheimer's time check and said that, no, there's nothing wrong, nothing wrong at all. I was, I'd really like to pay you for a brain scan or a full medical check-up to check that I'm okay. "You'll be wasting your money," he said. "There's nothing, you know, don't worry about it. There's nothing wrong." And that was probably two years previous. So anyway, back to Valentine's Day, I had this full medical and that included a brain scan, and that was good.

Julie Pankhurst (5m 24s):

That was quite important for me to have a brain scan to check there was nothing going on. And when I saw the doctor, there was a questionnaire that said fill out anything that's wrong that you're worried about. And I had got this wrong. No, no, no, no, everything is fine and there's a section like anything else, but, okay, well, here's the time to tell this person about my symptoms that I had been telling the doctor about all these years individually, but they've been bugging me. I've written the symptoms down because I knew I'd forget them all. So, things like that, memory, number one. Not being able to recall words, I've already said.

Julie Pankhurst (6m 5s):

Things like balance, pins and needles in my feet and in more regularly into my hands as well, including numbness as well started happening. I was on holiday, and I couldn't get my breath. I was walking down, and it really worried me because I couldn't swallow. So, and at the same time that this was happening, my husband had a pulmonary embolism, it turned out. He didn't actually know he had it at that time on this holiday and a few days later, we ended up being in the hospital and he had the pulmonary embolism. It was horrendous. So, I didn't really want to make a big fuss about the fact that I couldn't breathe.

Julie Pankhurst (6m 46s):

It seemed irrelevant at that time. And what other things, balance problems and things like that. That was the other sort of thing I had. So, I thought-- Oh, and urinary incontinence. Did I say that word already? That's a horrible thing. Anyway, I told the doctor about all these things, and she said, "Yeah, yeah. It's the menopause. That's what you've got. Have you thought about getting an HRT?" I said, well, I haven't really, but anyway, yeah, I thought it must be menopause too. I had to lie down and have an MRI, which apparently was going wrong. Everything was going wrong with the machine. It didn't seem to be going wrong and with hindsight, benefit of hindsight, I believe that perhaps they'd seen things on the scan that weren't right, so they were perhaps calling people in to look.

Julie Pankhurst (7m 34s):

I don't know. <Inaudible> I went to see the radiologist to discuss my brain scan and the doctor was there and she said, "Sit down, please, Julie." And it was very-- She didn't have the nice friendly sort of manner. It was very serious. And she had two scans up on the wall, projected onto the wall. And that was my brain and alongside of it was someone else's brain. And she was saying, "All right, as you can see on the side that person's brain, it got lots of white spots." Oh, yeah, yeah, doesn't it? Yeah. Well, you can see you've got some too. Oh, yes, so I have. I didn't know <inaudible> and this person's got MS.

Julie Pankhurst (8m 18s):

And your brain looks as if you need to see a neurologist. And they didn't quite-- They couldn't say that I had MS. They just suggested that it was quite likely.

Geoff Allix (8m 33s):

Yeah.

Julie Pankhurst (8m 34s):

And I did say countless, should I be worried about this? "Just see the neurologist," she said. "Just go and see the neurologist and they can talk about it." So, I got an appointment probably three or four weeks later I think it was to see a neurologist. This is a private neurologist. They're so busy. So, you can imagine how I was feeling at the time. Oh, my goodness. And he diagnosed, yeah. It was MS. And insisted I had another brain scan done at that hospital

privately because the other one apparently wasn't good enough. I don't know. And he'd said then when I saw him first time, he said, "Okay, so you have MS."

Julie Pankhurst (9m 16s):

Let me tell you about the different sorts. There's relapsing remitting and there's a primary progressive and secondary. And said starts to describe to you what the different sorts are. Let's hope you haven't got primary progressive," he said. Okay. So, two weeks later, I went back and the first thing he said is, "Okay, so have I told you that you got MS?" Yes. Yeah, you did. "All right. So, you've got primary progressive MS." <Inaudible> Oh my goodness, you know, this is-- My world fell apart. I was just a trembling wreck. Absolutely awful.

Julie Pankhurst (9m 58s):

So, yeah, that was back in February 2019. Then I went on and he suggested that I didn't stay with him in London because soon I wouldn't be able to travel into London without help, but I asked him how long I had got until, you know, what's my future going to be like. And the suggestion was I was going to need a wheelchair in probably five years' time. So I was, "Oh, okay. All right." And then he said that I would probably be able to-- It wouldn't be wise to go into London each day and I wouldn't have the support.

Julie Pankhurst (10m 43s):

I wouldn't have the support network of the MS nurse that the NHS would be able to give me. Okay. So, I signed up with the-- My doctor signed me up with an NHS doctor neurologist. First time I could see her wasn't until November.

Geoff Allix (11m 4s):

And when was this? This was Valentine's Day.

Julie Pankhurst (11m 7s):

<Inaudible> April, yeah. Well, that time.

Geoff Allix (11m 10s):

I had a similar experience in some ways because I went private for the initial diagnosis, which was-- I saw a neurologist, it was a neurologist because they suspected something was going on there. But that was an extra to which you pay for the only way to the other side of the county that we're in now. It's quite a long way away and the road is quite so. And then similar sort of thing, he said, oh, you need to be, you know, on the NHS. But actually, most of the private people also worked for the NHS. So, I'm actually with exactly the same neurologist and he comes to my local hospital, which is about a mile from where I live. So, I could even go private and travel an hour and a half to go to a private hospital, or I could actually go with the NHS and do it.

Geoff Allix (11m 53s):

And the only being I don't get is a free cup of coffee or something when I arrive. But actually, it's much easier and it's the same guy. He's exactly the same person that I'm seeing. So slightly bizarre. But, yeah, and so it does, so that took quite a long time. And so, you eventually sort of transitioned over to a more local person, but it took until the autumn or fall.

Julie Pankhurst (12m 19s):

Until November, yeah. And when I saw her and I gave her the same sheet of paper with my same symptoms, once I waffled on and she said exactly the same and the first thing she said, "Well, I don't think that you do have primary progressive. That sounds more like relapsing remitting to me." Because it wasn't just those symptoms, I told her. I told her about the episodes that I'd had before, where I was over in New York and I couldn't-- I've been walking for ages and the second day out with my daughter, I was thinking I need a stick because I couldn't walk down from the pavement to the road when crossing the road. It's really a struggle. So, I think I needed a walking stick.

Julie Pankhurst (13m 1s):

And she was, "Oh, mom, that's going to be so embarrassing. Don't you dare." You know, how old was she then? 15 years old, about 15 years old I'd say. So, from being told and believing all that time I had primary progressive, I have

now been told that I've got relapsing remitting. Now I don't know what I've got truthfully, and I haven't actually asked someone how can you tell it?

Geoff Allix (13m 23s):

Well, there's some questions where there really is a difference, and so there's Gavin Giovannoni, he's one of the top experts in the UK and he's questioning whether there really is any difference. And I think it's a bit different for everyone who's MS <inaudible>, yeah.

Julie Pankhurst (13m 38s):

Yes. Yeah. I mean, I think from what I saw primary progressive seems to be a lot worse.

Geoff Allix (13m 47s):

It is sort of rather than having a relapse and then recovery if you don't necessarily have the recovery. So, it's very progressive and that's a-- But then there's the people I've interviewed who have a primary progressive MS and they're very optimistic. Okay, you are not going to recover from relapse in the same way and you might not, you know, go back to running marathons as some people do, but you don't-- It doesn't mean you have to keep getting worse and worse and worse. So, you can look after yourself. And, you know, <inaudible> MS and I have a really, you know, fulfilling life. I was similar to you that I was really, really worried about until now I've spoken to those people and their life experiences are not nearly as bad as what you think it might be.

Julie Pankhurst (14m 32s):

And so, coming across MS? So, my husband's friend told him about it. I think it might've been related to the Sam Joseph's. He might've known <inaudible> Sam Joseph. So I think--

Geoff Allix (14m 48s):

He's a nutritionist too, yeah.

Julie Pankhurst (14m 50s):

That's right, yeah. I think she works in Muswell Hill. So, I think he'd known about her, but he mentioned to me about OMS. I looked on the website straight away, got the book straightaway. And there was a retreat that was in June 2019. And I went on the retreat in the July 2019. And it was by far the best thing I've ever done. I was so lucky to get on that retreat. I recognize that not everybody can do that, but it was amazing. I went in thinking my world had completely fallen apart and woe is me and, oh, my gosh, I'm doomed.

Julie Pankhurst (15m 36s):

So, I went in really feeling, oh, my goodness, I'm not going know anybody. I'm not going, not as much know anybody, but people I don't-- I don't know anyone, didn't know anyone with MS. And I had the vision that everyone is going to be severely disabled. I thought that I wasn't at that stage, but I thought I was going to see my future. Well, yes, there were people that were disabled, but they were just lovely, lovely people everyone we saw, and such positive people.

Geoff Allix (16m 9s):

Yeah. I think <inaudible> presumably Linda Bloom was there and people--

Julie Pankhurst (16m 12s):

No, she wasn't at the one I went to.

Geoff Allix (16m 14s):

Okay. But all the people who are involved in OMS, the facilitators, are hugely positive.

Julie Pankhurst (16m 23s):

Yes.

Geoff Allix (16m 23s):

And they have MS, but they're just not, you know, they don't see it as a horrific thing. And in many ways, it just sort of opens up their eyes to actually living better and there's a lot of positivity I think with all of those people.

Julie Pankhurst (16m 40s):

100 percent. I mean, it just shone through. I met with Phil who was the guy that does the meditation. A lovely guy and he had primary progressive and he was just like, gosh, wow. You know, there's a light at the end of this tunnel. And I came back home, and I was such a changed person. And my husband noticed it straightaway. I was positive. I was back to my normal self again. I really had completely, I don't know, my whole, everything about me had just died after the diagnosis. And then I went on the OMS retreat and I'm back to normal again, mentally, definitely.

Julie Pankhurst (17m 23s):

And I see positivity, I don't see this doom and gloom any longer.

Geoff Allix (17m 27s):

And for the OMS diet, so you've been a vegetarian. You've been a pescatarian.

Julie Pankhurst (17m 33s):

Yes.

Geoff Allix (17m 34s):

So, did you find it quite easy to transition into the MS diet?

Julie Pankhurst (17m 38s):

Yeah, so I was a vegetarian since 19 and actually, I was a pescatarian to start with a couple of years, then went full vegetarian, not vegan. And then when my second daughter was born and that was in 2002, I started eating fish because my first daughter was a nightmare with eating anything. So, we started giving her, you know, because I brought them up as vegetarian. Okay, it's not fair, but they have to eat, so I give them fish fingers. So, I ended having fish fingers myself. I'm thinking, oh, my gosh, I'm not religious. I looked up thinking there was going to be, you know, a bolt of lightning was going to come down.

Julie Pankhurst (18m 19s):

It's very bizarre. Anyway, so I then, yeah, I was a pescatarian for quite a while. Prefer it for ethical reasons. I was vegetarian, so I prefer not to eat fish, but anyhow, so turning, transitioning to go in the OMS diet, for me, I've also been quite headstrong with certain things like in 2000-- I can't remember. 2014 I think it was, I gave up wheat for a few years because I read this book, didn't read this book, heard about this book, bought the book, watched the YouTube because that's what I did.

Julie Pankhurst (19m 3s):

I'm not good at reading books, likewise with MS, watched the YouTube or listen to audio books or listened to podcast like this. And this guy called Dr. William Davis wrote a book called *Wheat Belly and My Stomach*. If I ate wheat, it'd actually balloon out? Quite a lot. And this is another story for another day, you know? But so, I gave up wheat so I should recognize that I could do. So, I recognized that was inflammation that was happening and then does that trigger for MS? Who knows? I mean, but I could do that. I gave up wheat. I had the edge. I had the mental capacity to do that. Then I gave up sugar. A friend of mine had a sugar addiction and I went with her to a sugar addiction weekend, which was really interesting.

Julie Pankhurst (19m 49s):

So, I gave up eating sugar, then come Valentine's Day. I started eating wheat. I started eating the sugar. I didn't give a flying monkey because I'd got MS. So, suddenly, wow. Anyway, so becoming vegan, the worst thing-- Not the worst, the hardest thing for me I thought was going to be stopping eating cheese because I love milk, cheese and wine parties, gatherings. Yeah. Cheese is--

Geoff Allix (20m 22s):

Actually, cheese is the hardest thing for me.

Julie Pankhurst (20m 26s):

Yeah. But I gave it up straightaway. After going on the retreat and listening to, I think it was Doctor Johnny. Johnny talking about dairy and how it gets through your leaky gut and how, you know, your body attacks that and then a similar sort of substance or some sort of makeup of the mind and cheese is similar, and that's why it attacks that. That's my understanding.

Geoff Allix (20m 53s):

Yeah.

Julie Pankhurst (20m 53s):

It's my crude understanding. Okay. So, cheese is going to be attacked in the same way. It starts attacking that, it's going to attack the mind and cheese. So therefore, don't have the cheese and then it won't start attacking you and go into--

Geoff Allix (21m 5s):

And there is-- I think you might have you met Josh <inaudible> the next thing about that, it's not actually natural. It considered a food group, but actually when you think about it, you having breast milk as an adult, that's not normal for any species. You're having breast milk as an adult from another species and no animal on earth does that. That's just-- that it's not really-- it can't be considered normal for that to be a requirement to have breast milk from another animal, because they have to artificially make the cows have breast milk by-- it really isn't normal.

Geoff Allix (21m 46s):

It can't be normal and a requirement for health. And when you think-- I know it's actually if you were to go out into the field and start drinking milk directly from a cow, you'd probably be arrested. It's not really normal. And then cheese is actually milk that's gone off. So it's got to be even worse, but, yeah, it is delicious, so it is difficult to trade off from. Yeah, I'm a fan of cheese <inaudible> but I'm the same way as you, once you sort of think this is actually doing me harm, then I just stop straightaway and haven't really had a problem to, and you just got used to it. And the idea of eating cheese now is completely anathema.

Julie Pankhurst (22m 24s):

It's quite gross now, isn't it?

Geoff Allix (22m 26s):

Yeah.

Julie Pankhurst (22m 26s):

It's just weird. I mean, the thing was I used to eat a lot of was chocolate, milk chocolate, and strangely, no, it doesn't bother me. It doesn't bother me about giving up milk chocolate either. Even chocolate I don't eat it because it's got the cocoa in it. I confess I've had a nibble, tiniest nibble.

Geoff Allix (22m 49s):

There are some good things in chocolate, which you can get from having cacao and so there are some ways of eating chocolate without having the fats. So from diet to exercise, I've heard you have quite an interesting fitness program. So, what was your fitness regime?

Julie Pankhurst (23m 14s):

I don't think it's interesting. I'm the most reluctant exerciser in the world I think probably. And I like doing exercise because I don't realize I'm doing it. So, I like walking because I don't see that necessarily as exercise especially if it's a means of getting somewhere. I didn't, to be honest, I didn't like walking too much because of my bad balance and things like that. But down to, you know, because we're in, you know, the pandemic at the moment, I've been walking

so regularly and actually really loving it and getting better at it on occasion, but I did fall over on Friday and fell flat on my two knees. A bit of dropped foot I think, but what I've really embraced and I can't believe I'm saying this is getting up at seven o'clock in the morning.

Julie Pankhurst (24m 3s):

I roll out actually at five past seven and I roll out of bed and at 7:30, I'm ready and I'm doing Veronique's Taming the Walrus yoga. Veronique, for people who don't know was one of the facilitators that the OMS retreat that I went on and she has MS, not that you would know it. She's just done a marathon, her first marathon, over in Portugal. So, a virtual marathon, I suppose <inaudible>.

Geoff Allix (24m 31s):

Well, she did during lockdown. Yeah, she did. She ran a marathon without the thousands of other people, but she did run a marathon but, yeah, it was without the crowd. Unfortunately, because of the pandemic.

Julie Pankhurst (24m 42s):

Well, she had us as supporters, people that went to her yoga, her morning yoga. Yes, well done. So, yeah, this has been really good for me because there's people there that understand. I mean, she understands so I don't have great balance, so she'll adapt things and I thoroughly recommend people. Although I love my small group because there's only about five or six of us who are on there at the moment. It's very new and I don't want it to get too big because it's very personal, but I'd love for people to actually join it because I think it's so beneficial. It's a lovely way to wake up. And she does other ones throughout the day too, but 7:30 is for me.

Geoff Allix (25m 26s):

Yeah. She does videos for our MS. In your professional past, you and your husband started a company in the internet boom, some 20 or more years ago, which you then sold in 2005 and could spend a lot of your time on philanthropy. And you are one of the supporters of this podcast for which we're very grateful. So why is philanthropy important to you and why did you decide to support OMS?

Julie Pankhurst (26m 7s):

Philanthropy, I just wanted to give something back. We wanted to give something back because we were really lucky to sell our company. And I'd been sponsoring a little boy through a charity called the Plan UK and that was back in the 90s. We'd write a letter. You could send a tiny, lightest weight present, really like piece of paper pretty much over and he'd write back. And it was pretty lovely, lovely charity. You felt that that money wasn't going just to him. It was to sponsor the whole community to get a well or a school or, you know, to build a school. And so, we got more involved with that and when we sold the company, the charity recognized that I had been sponsoring this boy through them.

Julie Pankhurst (26m 54s):

And they invited me along to an event at the House of Lords. And it's like, oh my God, the House of Lords. Oh, wow. This is amazing. So I went along to this event and met the CEO there who was lovely, and said, "Oh, I would love to go and meet him and that little boy." And she said, "Well, you can." We embraced the idea. We embraced the idea as sponsors meeting the sponsored children and meeting, going to the community and I said, "Well, I couldn't possibly do that without getting more involved". So, I did. I got more involved. We built a school, and I went to see the school over in Ghana.

Julie Pankhurst (27m 35s):

It was an amazing experience. It was amazing. I think it was good for them, but I think in this particular area, it was in Mangoase, which quite impressed me. I remembered mango who <inaudible> in the middle of a Ghana and, yeah, I think it was good for them. Well, obviously, it was good for them because they got a school. They treated us so lovely. They made me dance in front of the whole community. There are two communities that apparently weren't really actually getting on too well together, but the school had brought them together, which was a really positive thing.

Julie Pankhurst (28m 17s):

Yeah, so that was really good. And ever since then, we've carried on building schools in different parts of the world, in economically challenged countries so to say. And part of that is my family. We actually build a school. Then we'd go out and visit the community just for a couple of days, and then get to explore around that part of the world. And it's been amazing. That's been really beneficial to myself, my family and to the schools, and to the communities.

Julie Pankhurst (28m 59s):

So, I always felt guilty about doing it, but the CEO would say to me don't feel guilty because they're getting an amazing school. It's win-win. So, and then from that, I like to give, we like to give back to charities where it has a big impact, I guess, rather than just giving to someone. Just we like to give a bigger impact. So, this impact for the school, for example, many, many kids are going to go to the schools and benefit. And it's a way of empowering them. You know, education is key for people in less well-off countries to actually build a better future and become empowered.

Julie Pankhurst (29m 47s):

So, with OMS, I love OMS. Don't think you can tell, but I just think it's such an amazing organization. For me, it's changed my life. It changed my life so much that I want other people to benefit from it too. I think George's work doesn't seem to be recognized very much by-- I don't know why it's not recognized. I think it's perhaps because they can't do a study on people, on what they are eating, what people are physically eating, because people might go and start eating dairy and they can't control for it.

Julie Pankhurst (30m 39s):

There's no controls. Am I making--

Geoff Allix (30m 41s):

You can't really do a double-blind placebo control test on someone's diet.

Julie Pankhurst (30m 47s):

That's a very nice way of putting it. I know--

Geoff Allix (30m 49s):

You know which one is eating cheese and which one is eating beef and they-- So it's impossible really, but now it's getting slowly better. Let's just hope that-- I certainly hope more neurologists have heard of OMS and so hopefully, the more the message gets out, the more people are following it and then, yeah, maybe we get somewhere. The message is getting out. It's just a slow process, unfortunately, to acceptance.

Julie Pankhurst (31m 20s):

OMS is good not just for people with MS. The whole lifestyle is beneficial anyway, isn't it?

Geoff Allix (31m 26s):

Well, this is what my neurologist said to me. So, there is no proof that would help MS. But actually, it's going to help. It will reduce your risk of heart disease. It will reduce your risk for cancer. It will reduce your risk of-- It was a long list of things basically went through all of that sort of <inaudible> is and said, so this, you know, there's not really a downside. He said you might miss cheese, basically, it was the downside. He said literally that's it. He said it won't do you any harm. You make sure you're getting all your nutrients, but actually, being on that sort of diet and <inaudible>, no one's ever going to say exercise is a bad thing. No one's ever going to say that mindfulness is a bad thing and eating a whole food plant-based diet.

Geoff Allix (32m 11s):

Again, no one is seeing that it's bad to say it. So, there wasn't-- He said there was just nutrients. There was no downside, but we can't prove it will do anything with your MS, but it's certainly going to do you good just in a general aspect. And I found a lot of people have friends who've been through cancer diagnoses and other conditions, Parkinson's. So very similar lifestyles are recommended for them as well. And then you think that this similarity is

astounding. You think actually there is a connection with a lot of these things I think, you know, why is our body attacking itself? Because this is, you know, we haven't caught the disease from somewhere.

Geoff Allix (32m 51s):

This is our body doing to itself. And it seems to be a lot of these conditions where the body attacks itself to sort a completely different thing. I learned about a hobby that you had just connected with your work as well, a previous job, which is exploring family ancestry and that is connected with the internet company you founded. So, could you tell us a little bit more about your genealogical bug? Is that the right pronunciation of the word?

Julie Pankhurst (33m 20s):

You knew it too? I don't know. I wouldn't say it.

Geoff Allix (33m 23s):

Ancestry.

Julie Pankhurst (33m 24s):

It works for me, but I understand what you're saying. So back in 1999, if you remember that, I was asking my dad, my father's father left him when he was 7 years old. He went to live over in Denmark and I'd been asking my dad if he was interested in finding out what happened to his dad for many years. In 1999, he said, yeah, you know what? I wouldn't mind knowing, which is a bit strange. Not strange. It was not strange. So, there was a website and there weren't many websites back then, but there was one called phonenumbers.net. And I wrote, and I found on phonenumbers.net all the people that had the same surname, which is Hill, H-I-L-L.

Julie Pankhurst (34m 12s):

It's very common, but over in Denmark, there only seem to be about eight people with a surname Hill. So, I physically wrote a letter and posted it to the people that had that surname that I'm looking into my father's-- No, I didn't say that actually. I didn't give any information. I said I'm doing some research and trying to try to find this person called Harold Hill, would you happen to know who he is? That was on the Friday. On the Monday, there was an answering machine message. I'd come home from work. An answering machine message saying, I'm not related. I don't know this person, but I found it.

Julie Pankhurst (34m 54s):

I was so interested in your letter that I went to the local library and I phoned people with a surname Hill. I thought, oh, I can't believe I'm doing this. And the first person, no answer. The second person is his wife.

Geoff Allix (35m 5s):

All right.

Julie Pankhurst (35m 6s):

Oh, my goodness. Well, cutting a very long story short because it's quite a long story short, a long story rather. He died three months previous. She wanted to speak to me. She was happy to speak to me. She didn't know the reason for my interest, so I spoke to her. I was three months pregnant. I've been trying for a child for a long time and the butterflies, the anxiety was just off the wall, you know, of how I was feeling. I said, so, you know, she was telling me that he died three months previous. And she had said, "So why do you want to--? You know, what's your interest?" So I said, well, you know, he was married before in the UK?

Julie Pankhurst (35m 52s):

"No, I didn't know this."

Geoff Allix (35m 54s):

Oh, right, wow.

Julie Pankhurst (35m 56s):

Yeah. Oh, my goodness. Can you imagine? Oh, oh, okay. And I said, "Well, oh, yeah, he was. Do you want to know more?" She said, "Yes, I'm very interested." Oh, my goodness. So, I said, "Well, he had a son and I'm in his granddaughter." She was so lovely. I met with her. She came over when my first daughter was born at Christmas time. My father met her. She had no idea, could you imagine? So, this brought about my interest in genealogy, I guess.

Julie Pankhurst (36m 39s):

There was more that happened since then. And I was down in Devon quite a few years ago, so my dad has discovered he's got a sister. He's an only child, always been an only child. He's got a sister over, not by this lady, but by someone else. My grandfather had married over. I don't think he married. I don't know a common law in Denmark. And we met her, my dad met his sister for the first time back in 2001. And then later, I've got a phone call and through a site called Genes Reunited, which was my husband's site.

Julie Pankhurst (37m 22s):

It was our site, but Friends Reunited was mine. And we've always got these one-upmanship relationships that he wants to get one better. So, he created Genes Reunited. And through Genes Reunited, this woman had phoned me up to say, I think that we've got it-- Oh, no, she sent an email saying I think we got our relation in common. We share the same grandfather. I was, oh, my goodness. And it turns out that her grandfather is my grandfather. We spoke. Her mother is one month younger than my dad.

Geoff Allix (37m 58s):

Oh, right.

Julie Pankhurst (37m 59s):

He worked that one out. So apparently, what had happened is it was in the wartime. My grandfather had a couple of relationships, obviously.

Geoff Allix (38m 11s):

He had a few relationships.

Julie Pankhurst (38m 15s):

A few actually. And, yeah, so through Genes Reunited, which is the site that my husband setup or we setup, I discovered that I also had an auntie who's in the UK, that lives in Waterloo.

Geoff Allix (38m 30s):

Right, right.

Julie Pankhurst (38m 31s):

And, yeah.

Geoff Allix (38m 34s):

And you find it really interesting to research all of this?

Julie Pankhurst (38m 37s):

I love all of that because that's what my mum and dad are called Pat and John, and his sister is called Pat and her husband is called John. I love that fact. And then, since then it's just really interesting to find out about your family history.

Geoff Allix (38m 54s):

Back on our topic of MS, and something topical at the moment because we're still going through the COVID-19 pandemic. But now vaccines are coming around and you've been vaccinated against coronavirus, but the disease-modifying therapy that you are on has a strange effect on your antibodies. So, could you share some thoughts on

your experience and how vaccination, something maybe needs to be considered for people with MS and particularly following the disease-modifying therapy?

Julie Pankhurst (39m 34s):

Okay. So, I had both the vaccines. I had to push to get the vaccines because I was told I was going to be at higher risk. And I was in between infusions, some of our Ocrevus infusions. So, I had to push to go get it done in time and have the second one done in time, because you had to have it four weeks before infusion. And then I had the Ocrevus infusion, and I asked if I could actually have the antibodies tested beforehand to see that it was working. But that wasn't, you know, that wasn't a done thing.

Julie Pankhurst (40m 15s):

I guess, I don't know, you had to go through trials or I don't really understand why I couldn't have it done, but I guess-

Geoff Allix (40m 23s):

I think that maybe if <inaudible> could make it <inaudible>.

Julie Pankhurst (40m 26s):

Yeah. I guess that was it. Yeah, I felt exactly that right actually. So, I had the Ocrevus and then I've been reading by- I think it's on Twitter, Dr. Beaber and Dr. Boster. And I do look at Twitter a lot to get up-to-date information. I find it really-- I'm really thankful for the neurologist, especially over in America and Dr. Giovannoni <inaudible>.

Geoff Allix (40m 57s):

Gavin Giovannoni, yeah, he's talked a lot actually about how the vaccines might work, especially with Ocrevus or Ocrelizumab.

Julie Pankhurst (41m 6s):

That's right. It's the ones that target the CD20B cells apparently. And that only yesterday, someone that I met on the OMS retreat, we're in a WhatsApp group and he sent a link that I had looked at this morning, a link to the MS society and they've actually put an article about it and saying, yeah, they know that Ocrevus, this is my understanding anyway, they know that the B cells, no, the antibodies, sorry, let me start. They know that the COVID antibodies are removed with Ocrevus, but they reckon that on the majority of the studies they've done I would add that of my, and definitely I had to do the antibody tests.

Julie Pankhurst (41m 54s):

So mine have-- Just I've got no antibodies for COVID at all. But today, they're saying that we do have the T cells and maybe they don't know that T cells can target, you know, the COVID as well.

Geoff Allix (42m 11s):

So, I mean, yeah, I think that's the takeaway I've had similar to you for sharing that with people on Twitter and that you should consider if you've had Ocrevus or you're having Ocrevus that it's likely to reduce your immune response to the vaccine. So, it's something where you shouldn't think that I'm fully vaccinated, I'm going to go into a nightclub tomorrow night. You may be under more risks than other people who've been vaccinated. But, yeah, you need to speak to your neurologist as well. And when you think that they're learning as well, don't they? I mean, it's, you know, when do you have the vaccine? Do you need a booster vaccine?

Geoff Allix (42m 53s):

I certainly was speaking to a neurologist about and certainly, definitely worth keeping on how they're planning and whether you need booster shots and things like that.

Julie Pankhurst (43m 2s):

Yes, a real pain because I'm due to go to my nephew's, I hope he doesn't listen to this and I don't think he will. It's a surprise party that was on the 14th. Yeah, hopefully he won't listen to this, but I'm due to go to a surprise party for

him. And then I'm due to go to a large wedding and the week after, and both of them, I'm just thinking, I don't think I should be going. I think I'm too at risk. I don't like that. I don't like being--

Geoff Allix (43m 34s):

No. I mean, that will become a point I think we're in the UK we've done or the one that we're done through them actually is vaccination. Having done badly over the other past the pandemic, but there will become a point where there's enough people vaccinated that you will be able to lower the risk because of the rest of the population as well. So there is that, but I think, yeah, I think it's something just to be aware that people might need you to just be a bit more careful and, yeah, carry on with some of the things we've been doing, but hopefully, they'll work out how to get everyone's antibodies up.

Geoff Allix (44m 16s):

But they're certainly looking into it. I know it., But it's all new, isn't it? Two years ago with this that happens so.

Julie Pankhurst (44m 24s):

And I'm hoping that the people with MS are going to benefit from some of the studies they're doing with COVID.

Geoff Allix (44m 30s):

Yeah, this is the bizarre thing. The vaccine techniques they've used actually might help all sorts of things including MS. So, this mRNA technology we've used to develop vaccines so quickly actually might help for all sorts of different conditions. So, yeah, there could be some real positives from it.

Julie Pankhurst (44m 48s):

Yeah, I hope so.

Geoff Allix (44m 52s):

And we were very grateful that you've joined us on Living Well with MS Coffee Break. And one thing that we do ask people, our guests on this, is if you have any advice for people who are newly diagnosed or newly following OMS that would help them follow the OMS program?

Julie Pankhurst (45m 16s):

What advice... I think the OMS program enables you to be proactive, enables you to take control over your life. That's my biggest takeaway from OMS, and rather than waiting for your yearly or however long it might be an appointment with your neurologist, you can do something about your life now. And to get involved with a circle, get involved with a support group. I'm involved on WhatsApp for the people that went to the retreat I went on. It's great. We actually, I know you just ask for one bit of advice and I kept on, but we shared recipes.

Julie Pankhurst (46m 1s):

We shared problems and ways that we get over these problems, MS-related typically, but any problems. But I would say the OMS Circles are--

Geoff Allix (46m 17s):

Yes, and it's worth, if you have a look on the OMS website and look at our resources and circles, you, you'll find that they're around the world, but there are some places that have many more circles than others. But one thing that I can share is that there is a new circle being formed for people who are a long way from anyone else. So generally, they're geographic circles, but they are starting new circles. There's one for people with primary progressive MS just because they might want to talk with each other. They've got particular issues. And also there are going to be wonderful people who are not near anyone else geographically. So traditionally, they were set up for people to physically meet, because of the pandemic that's happening less, obviously.

Geoff Allix (47m 1s):

But, yeah, there will be a new circle forming for people from far-flung areas of the world, so to have a look and don't think, oh, because there isn't one near me, I can't join that because it's been really beneficial for me, as well as having

lots of people who understand what you're going through and it's very difficult. I mean, members of your family don't fully understand what you're going through, unless, you know, if they're not going through it. So, it's really nice to have people to talk to who have similar experiences.

Julie Pankhurst (47m 29s):

Oh, I would wholeheartedly say that. I mean, people in our group, there's a lady who was in Mexico, someone's in California, and someone in Germany, and we all communicate. And someone else's in Brussels and it's pretty-- It's great. You don't have to be the power. That's the positive that's come out of COVID in a way. You've got Zoom and we all use it now. Now I'm talking to you on Zoom, and we're now connected in a way. It doesn't matter where we are in the world. And that's the real positive, definitely.

Geoff Allix (48m 2s):

So, with that, thank you very much for joining us, Julie Pankhurst.

Julie Pankhurst (48m 5s):

Thank you. Thanks for having me, Geoff. It's been nice talking to you. I hope I didn't waffle too much.

Geoff Allix (48m 11s):

Thank you for listening to this episode of Living Well with MS Coffee Break. Please check out this episode's show notes at www.OvercomingMS.Org/podcast. You'll find all sorts of useful links and bonus information there. If you'd like to be featured in a future Coffee Break episode, or have any suggestions, please email us at podcast@OvercomingMS.org. You can also subscribe to the show on your favorite podcast platform so you never miss an episode. Living Well with MS Coffee Break is kindly supported by grant and the Happy Charitable Trust. If you'd like to support the Overcoming MS charity and help keep our podcasts advertising free, you can donate online at www.OvercomingMS.org/donate.

Geoff Allix (48m 56s):

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