

S3E41b Transcript

Coffee Break #22: Jen DeTracey

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 (46s):

So, get your favorite drink ready and let's meet our guest. On this episode of the Living Well with MS Coffee Break, I'm joined by Jen DeTracey. Jen's bounced back from her MS diagnosis to author a book on marketing called Lift Strategies and launched a health coaching business called Women Thriving with MS. So, Jen, welcome to Living Well with MS Coffee Break. We're so pleased to have you on our program and the purpose of the Coffee Break series is to get to know some of the MS community from around the world. And so today is your turn and could you tell us all a bit about you, where you're from, what you do and so on.

Jen DeTracey (1m 26s):

Yeah. Hi, Geoff. It's great to be here. And I'm from-- I've been living in Canada for most of my life. Right now, I'm in Montreal and I came from a family of four kids. I'm the only one with red hair and I was the runt of all the tall people. And what's interesting is my father was in the Canadian Armed Forces. So, we moved around a lot, around Canada. We were down in the US in Alabama, which was shocking to me as a Canadian, for a year, as well as in the UK when I was six. So, I had many different schools and was constantly adapting to change. And at 21, I fell in love, but it was with marketing. I attended a business college.

Jen DeTracey (2m 9s):

Yeah, I was my love at the time. And when I graduated, I actually started to do college radio, which was really exciting. I sort of dove into music in a very deep way. And my dream was to work for a record label. We had a small one in Canada, an independent, still exists called Network Records. I don't know. Have you heard of an artist called Sarah McLaughlin?

Geoff Allix (2m 32s):

I'm aware of the name but I can't think of anything she's done.

Jen DeTracey (2m 36s):

Yeah. Well, you know, she's kind of been there, done that now, but back in the day because, I'm 55 right now, back in the day when I hopped into the music business at 26 and was doing that, I was doing marketing for her and that was a blast. In fact, I was in the music business for 10 years until things moved more to digital and dotcoms were dying. And I started my own business and that was a marketing strategy business. So, and I've been doing that online actually. I switched to moving to only meeting with clients online about six years ago, long before COVID hit, as a way to manage my energy.

Jen DeTracey (3m 21s):

And so, I'm doing that presently and I basically aim to work about 20 hours a week and I also started, but I know we'll get into this later. I started the Women Thriving with MS Community. So, we can chat about that in a bit.

Geoff Allix (3m 38s):

Absolutely. And then when were you diagnosed with MS?

Jen DeTracey (3m 42s):

Yeah, it was back in 2010, so almost 11 years ago now. And ironically, it was like at the busiest time of my life, darn it. I was on a three-day speaking tour and right before I left, I noticed I was hugely fatigued and I was just like, okay, I'm just tired because I'm working a lot, like 10-hour, 12-hour days. And, you know, my left hand was acting a little funny and I was kind of like, what's going on with that? So, when I did the tour, it was very compressed and crazy. And I got up on the second morning of that tour and I just was-- I was like, I'm so tired.

Jen DeTracey (4m 23s):

I've got to get out and run because I need to get some energy. And I was running, my left foot started to drop. And I actually, I thought it was hilarious. I'm like, this doesn't hurt. So, what's going on here? But I felt I did have to hide that while I was up speaking with people. Like I had to put a table in front of me, so they couldn't see my leg on day three, which was kind of hanging a little bit. So, when I got back to-- this trip was in Northern Canada. And so, when I came back home where I was living in Vancouver at the time, the next day I went to my naturopath and I went to my physiotherapist to try and get me in shape.

Jen DeTracey (5m 7s):

And they said, "You know, if there's any problems, just come back on Monday. We think there's something in your C3, C4 area of your neck. So, we'll check that out, you know." Again, in the meanwhile, I had plans on that Saturday. So that was on Friday. On Saturday I had plans to go see a play and I met up with a friend and she said, "What's going on with your leg?" And I said, oh, don't worry about that. Like, let's just go in and watch the play. And she's like, "Well, you know, I think you need to go to Emergency." So, I said, well, let's watch the play first. So we went into the play, had dinner because, you know, you can't go to Emergency before having something to eat because you never know how many hours you're going to be in there for. You can't go on an empty stomach.

Jen DeTracey (5m 47s):

Yeah. So that's what we did. And so, I was fast-tracked and that night at the hospital, they had done all, everything. And then they've moved me into a holding tank area and they said-- I said, "Excuse me, can I go home now? You've done all these tests." They're like, "No, we're going to page a neurologist to come in in the morning." And I'm like okay. Like I was clueless. What does that mean, you know?

Geoff Allix (6m 12s):

And when you think it might be bad because I've been through the whole chiropractor, osteoporosis type thing that it could be a trapped nerve. And equally, I had a dropped left foot early on, which I discovered from running because I used to do a lot of running and you, yeah, you're expecting it to be a trapped nerve because-- And a lot of sort of chiropractors or osteoporosis people are sort of saying, "Oh yes, we think it's trapped nerve here that's causing this." And so, yeah, to then be told that you're going to see a neurologist, you know, why we would have to see a neurologist? So, I can imagine. But how was the health care system in Canada for treating MS?

Geoff Allix (6m 53s):

Is it pretty good?

Jen DeTracey (6m 54s):

Yeah. What's interesting is it is pretty good in some ways. If I can just, I want to backtrack for a sec to-- So what happened there in that situation was that I was diagnosed within 48 hours with MS. And then they put me on the steroids, gave me the lumbar puncture and everything. And what I found was that I was so pumped up on those steroids that I couldn't sleep, and I felt crazy and that's kind of how I left the hospital, you know, in that state of shock. So, when we look at the healthcare system, I can say that, yes, like I was able to access a neuro and this neurologist, she was great.

Jen DeTracey (7m 38s):

I was so lucky to get her, you know, in the lottery of neurologists. When I left the hospital though, they don't prepare you for anything. You know, I'm pumped up on steroids. I'm in shock. They don't talk to you about diet or next steps. They just say, "You know, here's a piece of paper with some information on the MS Society. And you're going to see a neurologist in three months and just carry on with your normal life."

Geoff Allix (8m 4s):

So to speak the medical part was okay, but the support side of it was maybe a bit more lacking?

Jen DeTracey (8m 12s):

Yeah. There's nothing in place and you know, I think that this is 11 years ago. And I think now with hospitals in Canada and, you know, they're being sort of a stretch of, you know, not as many resources available because the demand for serving people is so high that I don't know if that will ever happen. And that's something that I would like to see change in that industry. It's amazing how you could, if you could just sit down with somebody and say, "Okay, yeah, like this is shocking for you to go through this and here are the next steps that will be happening for you," I think just a great entry point into starting that new journey.

Geoff Allix (8m 53s):

Yeah. I mean, I don't, I've spoken to people from lots of countries now, and I can't think of anywhere that they've said actually that there was someone who gave that sort of support. I mean, there was an element I had of that sort of support, but it was from a neurologist who really had been through the process many times before, but he wasn't trained to give the emotional support side of things. So, yeah. And I'm not aware of any country where they do, to be honest, certainly no one's told me about it, but you're right--

Jen DeTracey (9m 24s):

I think in the US, yeah.

Geoff Allix (9m 26s):

I was just going to say, yeah, you're right. It would be hugely beneficial.

Jen DeTracey (9m 32s):

When I have-- I've had a conversation more recently with a woman who's an MS nurse in the US. She's actually retiring, but there's a whole body of MS Nurses internationally. Most of them are in the US and Canada. And I think that they are more astute to important information beyond the medical side of things for MS. But in Canada, we don't really have that structure in place. And I'm curious in the UK, if you have something like that.

Geoff Allix (10m 4s):

We call it a postcode lottery here. So, it is dependent on where you live really. So, some, I mean, we have a great health care system with the NHS. It's free of <inaudible> views and that's, you know, very effective. And I think a lot of people, myself included might have private healthcare, but that actually find that the national NHS system has been the main thing that they're using, but it does depend on where you are. You certainly get different treatment. And if you're in different parts of the UK, so Scotland has different medications allowed as opposed to Wales, which has different medications allowed compared to England.

Geoff Allix (10m 45s):

So, it does very much depend on where you are. So, after diagnosis, what's next? So, what changes did you make? How do you deal with the reality of having MS?

Jen DeTracey (11m 2s):

Yeah, you know, at that point, because I was at the peak of my career, I really didn't have-- I had enough time to take a break when I came home from the hospital for maybe two to three weeks. And that's because my daughter who lives in Spain, I had a plan to go visit her, but I knew I couldn't. It just wasn't really, I didn't have the capacity, the energy, and after, you know, being on these steroids. So, I basically used that time to recover, but I had six months of training contracts where I would go and do full-day trainings and also regular clients. And so, I had to figure out how can I make that work.

Jen DeTracey (11m 43s):

Because one day, a full training was very difficult. So, I just tried to space them out in a way where I didn't do two days in a row anywhere. And the challenge for me was because I had put so much time and energy into my business in the last three years, leading up to this situation of being diagnosed, that it was completely my identity. So, it was very hard for me. And I took naps every day, but I was reluctant at that point. I've surrendered to that now. Naps are like awesome. But back then, I was just like, why do I have to take these naps? So, you know, by the time I finished those contracts and was just pushing through in my MS denying state of mind, I just hit a wall and, you know, I could barely get out of bed.

Jen DeTracey (12m 31s):

And, you know, I think the biggest fear was losing my mobility. So that's kind of where I landed. And then I had to, you know, really had to look at things and figure out how to do my life differently because denying MS was not working for me. And living in that vacuum around living with MS and fear was just, you know, it was kind of basically purgatory, right?

Geoff Allix (12m 54s):

So, what did help with managing the challenges of having MS?

Jen DeTracey (12m 60s):

I think for me, I was really lucky because my neurologist, first of all, told me when I met with her at three months, she said, you know, often people will grieve their diagnosis for up to three years that she has seen that. And it was really helpful that gave me permission to be able to grieve. It gave me permission to acknowledge that being diagnosed with MS can be traumatic. And so, I just had to make some changes in my life. And also, people were making changes on my behalf. I don't know if you've heard the stat that 75 percent of people that get diagnosed with MS lose family members or friends, because those people can't handle it.

Jen DeTracey (13m 42s):

And that happened to me. I had some, a friend that I was hanging out with that I lost. She just couldn't handle it. I quit running, which I had been doing training for a 10K because I couldn't. So, I had to look at like what could I do? Who was I as a person if I wasn't going to be able to work anymore? That was a possibility. And if I was not going to be able to run anymore, which was my way to distress, you know, how was I going to change that? I know. Did you go through some bumpy times yourself, Geoff?

Geoff Allix (14m 14s):

Yeah, certainly. I went from being very active, so running the marathon. Not long before diagnosis, I used to surf, rock climb, mountain bike, snowboard, and a lot of those things. I'm not entirely ruling them out. I mean, I've been snowboarding since diagnosis, but that's come become harder recently, but, yeah, it's difficult. When that's kind of your, that, as you said, that my life outside work was sport. And a lot of that's become harder. So, yeah, you do have to work out, but you have to work out.

Geoff Allix (14m 56s):

What can you do now? Rather than think about the things that I can't do, I'm thinking about the things I can do and trying to expand the things I can do.

Jen DeTracey (15m 5s):

Absolutely. I think that's, you know, in that soul-searching that I had, where I was deep-diving and asking myself who am I now? Like, who's Jen DeTracey now? And at that point, I decided, you know, one of the things was I needed to feel positive and hopeful. And so, I just kind of had my connection with God in the way that it was. I wasn't really a church-going person, but just that and getting into spirituality. And I had already been doing meditation, but I knew that I needed to get back into that. And I started to get back into my stretching and meditation routine because that was something I was doing before diagnosis to have that in my toolkit. And also I realized that I needed some therapy and the therapist that I picked to help me deal with my anger and upset around the MS just happened to be Buddhist.

Jen DeTracey (15m 56s):

And she really taught me about how to embrace feelings. So instead of being angry and pushing MS away, which wasn't really working for me anyway, pushing it away, it just got worse was that I just had to acknowledge those feelings around it. And by bringing those feelings closer, as opposed to pushing them away, they were able to not feel so big and diffused. And that got me to the place of acceptance around living with MS. So instead of having this relationship of hate or anger towards MS, it was, you know, it's not like I always liked it, but I could accept that it was there. And I think that was a huge, huge turning point for me to realize that MS is a part of me, but it's not who I am.

Jen DeTracey (16m 43s):

So, when people say I have MS, I don't-- for me, I like to say I live with MS, you know. That just feels better for me than saying I have it, you know. I don't know. That's what's feels comfortable for me.

Geoff Allix (17m 1s):

I think a lot of people put that as an acronym of PwMS, People with MS, that you're with MS, you don't have MS. But I mean, yeah, I guess it's just words, but I think it's a mindset thing of how you think about it as much as anything.

Jen DeTracey (17m 18s):

Exactly. To me, it's a mindset thing. And, you know, as part of what I started to do is I started through my therapist. I started going to silent retreats and they were kind of nice because I could have that time to soul search, but I was getting fed by someone else. I could sleep as much as I want, and I had a spiritual director that I could talk to once a day. And I did three 10-day silent retreats over a period of time. And that was really, really great for me and I realized instead of running, I could ride my bike, even though in the first few years, I did have some topples, but I'm good now. And I got back into swimming, and I've always loved walking. So, all of those things seem to work.

Jen DeTracey (17m 59s):

And the only thing that seemed to be getting in my way were vertigo relapses, which in retrospect, back seven years before I was diagnosed, I had a vertigo relapse so bad that I had to be wheeled into the hospital. Like I was just like throwing up everywhere. I couldn't like sit up or anything and had to be put on some kind of drip to calm me down. So, relapses, vertigo relapses have been with me. I have a lesion on the eye center in my brain. And when they were, they are nowhere near like they were in the past. There was one I had, it was so bad. All I could do is lay on my bed or on my floor and listen to audiobooks like Phillip Pullman's Golden Compass, you know, so that's what I did, you know.

Jen DeTracey (18m 47s):

I'm like, I couldn't go outside at first because the light in my eyes was too intense. And so, I just, you know, I was kind of rolling with it and I was living by myself. So, it was a very kind of lonely time, but it was a time of incredible reflection and just figuring things out for me.

Geoff Allix (19m 6s):

And could you tell us about your book Lift Strategies, and why you decided to write that?

Jen DeTracey (19m 13s):

Yeah, that's a great question. And the thing about the book was because I had been experiencing these dark times of being in this dark place. In fact, you know, there was a time in the beginning where I felt suicidal because I felt that the rug had been pulled out under me. But basically, I just asked myself, what is it that I want to do that I haven't done yet? And because I had been out there speaking and technically professional speakers have a book, I decided I'm going to publish a book. And so, I had all these weekly blogs that I'd written for seven years from my marketing strategy business, and I revamped them, and I hired a person to create the book cover and to edit, and all those kinds of things to make that book look really stellar.

Jen DeTracey (20m 1s):

And, you know, that really helped me get back on track. And I also reduced my work hours and I set a goal for myself. I get that book done in a year, to me 18 months because I had some bumpy periods, but, you know, the day that I

had my book launch at a little café and brought friends and colleagues that was a pivotal time for me. It's like I hadn't gotten through the hardest part of my life. And I had created something and put my focus towards it. So really it was just for me, that book was-- it saved my life. That's what it did. It saved me and it put me in a positive frame of mind, and it gave me a purpose. And I think that having a purpose is so important to healing.

Geoff Allix (20m 43s):

And the other key thing in your bio mentioned is that you founded Women Thriving with MS. So, could you tell us a bit about what Women Thriving with MS is and the impact that you hope it will make?

Jen DeTracey (20m 59s):

Absolutely. So, my mission, the mission with Women Thriving with MS is to guide women who are surviving with MS to connect with others and discover how to thrive with MS. And when I say thriving, what I mean is living that best life with MS. And this idea came to me at one of my silent retreats. Actually, I was getting some healing touch on a table, and I had this voice come to me saying I could do something more purposeful. And I was really curious about that. What would that be? And so, I walked the labyrinth, and I went up to my little room at my desk, in my little room. And I started to think about why is creating an online community of women living with MS important to me?

Jen DeTracey (21m 47s):

And I think I just wanted to create a space for women to feel they belonged, that they mattered, that there was something for them that may be in their day-to-day life, they didn't feel sometimes understood by the people around them, or they didn't have the encouragement of others who know what it's like to live with MS. And so that's kind of where that came from. And I just feel that having-- I started off with a private Facebook group and during COVID, I invited women to gather on Zoom.

Jen DeTracey (22m 28s):

And women really liked it. And I took them through the coaching experience. And this led to me starting a membership called weTHRIVE, which I just had the first opportunity to open that up in April. So, I have members in there now and, you know, basically, I take them through a process where they focus on one key area of their life that they want to focus on for a six-week cycle. And then every three weeks we meet online, and we see, you know, where the barriers are, where they're breaking through, and look at mindset. And we celebrate those wins no matter how big or small.

Geoff Allix (23m 12s):

Okay. We'll add links in the show notes if anyone wants to look for more information about Women Thriving with MS. There's links available there, so definitely worth checking it out. And that sounds like a great approach. I think, you're almost setting your own target, but then helping each other to achieve those targets, no matter how big or small they are.

Jen DeTracey (23m 33s):

Exactly. And that's why as part of the membership for women that want to participate, not all do, they can be part of a buddy program so that they have weekly support from one another. And one of the members, and what she said was she loved the accountability buddy group, because it keeps her honest, you know. We can say, yeah, yeah, well, I did my exercise or whatever, but when you're in an accountability group, it's like, you know, you can be a little more honest about where you're at, right?

Geoff Allix (24m 4s):

Yeah. Especially actually works well I think now because of COVID and the virtual world that we have, that if everyone's joining up remotely, then actually it doesn't matter. You don't have to be physically living in the same town being somewhere else is sort of normalized in community, hasn't it?

Jen DeTracey (24m 23s):

Absolutely. And if you think-- Yeah, totally. And, you know, Geoff, if you think about it, I mean, there's so many people that live with MS that live in small towns that don't necessarily have the resources, that don't even have, you

know, because depending on their income, they may be living in a place where the hospital or different things are quite far away. And so, what is there for them if everything's in person?

Geoff Allix (24m 50s):

So, to wrap up on the things you're doing for the MS community, if there's one thing that could be your legacy for your impacts on the MS community, what would that be? What would you hope that would be?

Jen DeTracey (25m 4s):

Yeah. To me, that's creating a movement for women with MS together from all around the world to support them in just living their lives better with MS. That's really what I'm aiming for as my legacy.

Geoff Allix (25m 18s):

Okay. And what are you planning next?

Jen DeTracey (25m 22s):

Oh, there's always something, Geoff. What I'm going to do is in October, October 18th, I'm going to run a two-week event that's going to happen on certain days called Women Striving to Thrive with MS and it's going to be a coaching sort of two-week period so that people can just hop on and experience that. And if they want to, after that, they can join the women. Pardon me. They can join the weTHRIVE membership when the doors open because I only open the membership twice a year. So, they only have a couple of times when they can become a part of it.

Geoff Allix (26m 3s):

Okay. That's worth knowing. But presumably, all the information is available online about how you go through that membership process.

Jen DeTracey (26m 10s):

Yep. It will be in the links below, and at www.womenthrivingwithMS.com and so on.

Geoff Allix (26m 15s):

And there's a question that we ask all our guests on the Coffee Break, which is that if you were to think about one nugget of wisdom that could help people, maybe the newly diagnosed, adapt to the change they need to make to their lifestyle, to their mindset, to live the best life they can with MS, what would that advice be?

Jen DeTracey (26m 40s):

Okay, well, I'm going to cheat and have three little nuggets if I can.

Geoff Allix (26m 44s):

That's fine. Absolutely.

Jen DeTracey (26m 47s):

So, number one is the slow down with MS. You know, take the time to rest and nap. And before you crash, build that into your life. It can be very restoring and help with the mental health. Then number two is trust yourself. You know your body, especially when you live with MS. You really get to know your body and you know what's best for you. And the last one is number three, which is know that we're better together when we live with MS. Living in a vacuum is a lonely place. I know because I've been there and if you're not already part of an MS community, find one that's a good fit for you, like Overcoming MS, Women Thriving with MS, because we matter.

Jen DeTracey (27m 38s):

And, you know, it's important to have that support and belonging so that you can heal and be healthy and experience harmony.

Geoff Allix (27m 48s):

Yeah, absolutely. I mean, I think because I came across Overcoming MS very early, then I felt part of a community, but I mean, I don't know what it would be like, but I imagine it would be really difficult if you were diagnosed and you saw your neurologist maybe every six months and in between nothing, that complete vacuum of support. I mean, the support is there, if I can go to the hospital, I can see an MS nurse, but these are things that I have to ask for. I can imagine that people could just be sitting at home, see their neurologist, maybe even annually and in between that having no experience, because I don't have a sort of Overcoming MS community.

Geoff Allix (28m 33s):

I don't know anyone else with MS. My father had MS, but that was many years ago when he died. So, yeah, it would be very lonely. I think you're absolutely right. But for that community, and slowing down as well, that's a really useful bit of advice I was given actually from my first visit to a physio, since I was diagnosed with MS, who actually said, "You need to stop worrying about things like speed and time and things like that." For example, don't worry too much if you're late occasionally. He said, "Honestly if you're late, what's the worst thing that could happen?" So, he said, "Getting stressed is more of a problem for you than actually being late."

Geoff Allix (29m 16s):

So, assuming you don't work as an ambulance driver or a fireman, then being late is not a big issue." And he was absolutely right. Actually, yeah, you can say to someone, "Yeah, I'm sorry. I was a bit late, took me a bit longer getting out of the house," which it sometimes does. And people will accept that. It's not a big thing. It doesn't really matter too much, assuming you're not in a time-critical job obviously. Yeah, but absolutely. Thank you very much for that. And with that, I'd like to thank you for joining us, Jen DeTracey.

Jen DeTracey (29m 52s):

Thank you, Geoff. It's a pleasure being here today.

Geoff Allix (29m 54s):

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Geoff Allix (30m 38s):

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