Yes - Recovery From Progressive MS Is Possible Transcript

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Introduction and Dr. Tayloru2019s MS Story

Welcome to the MS and Neuroimmune summit. I'm here with my colleague and very good friend, Dr. Folake Taylor. now, she, like me, is an internal medicine physician who, you know, study a lot, was thriving in her practice.

And then she began having these symptoms, which would ultimately be diagnosed with progressive MS And like me, that's when the next round of education began.

And it's really transformed her life. she's going to tell us her story. She's inspiring. She's doing really wonderful work. and, with that, I'm going to hand this back over to you.

D.r Taylor, Folake. So, without your introduction. And then tell us your story of transformation. So thank you, Terry. It's always an honor to be in the spaces with you.

And, Yes. So, like you said, internal medicine. I used to practice internal medicine, basically, but, now, and miss recovery expert and educator and, how that came about is because I did get diagnosed with primary progressive MS And let's stop for a moment.

Yes. I'm very progressive. MS This is a much, much worse diagnosis than relapsing remitting because it's just relentlessly downhill. And for most people there is no hope.

You just try to slow things down. And now back to you for like it. Yes. it is you know, it is a really it's not a great diagnosis to get. If I can put it that way.

But, what it is as my symptoms started, you know, going back a little started when I was a child. And then the first time I saw a doctor for symptoms related to M. S.

was actually in my late teens in the UK. I was there for the summer, you know, trying to do this summer jobs that required my hands and everything, and I was having the symptoms in my wrist, I had pain.

I was trying to learn typing in night school, night college, and that wasn't working out either. So I went to see the doctor, and of course they did all these rheumatology tests and everything.

It all came back negative. So at that point, my diagnosis was no sign of virus, which just means inflammation in the tendons of the wrist. But then fast forward a few years later, I was back in Nigeria.

I was in med school at that point, and I started having, you know, even worse symptoms in my wrist. And at that point was when I was diagnosed with, carpal tunnel.

Nobody was blinking MS or anything like that. So it was carpal tunnel. I even had surgery, which at that point only took care of my acute symptoms when I was trying to lose function in my left hand.

Early Symptoms and Misdiagnosis

But, the chronic symptoms were still there. And, basically, I decided that I was not going to go into a surgical specialty because I didn't know what would happen with my fine motor skills.

So basically, as far back as you know, my mid 20s, it had been a sort of, disability that affected the, you know, direction of my life. fast forward a few decades.

a month after I turned 40, I herniated, two discs in my lower back. And, that's when everything started going

downhill. I was told, yeah, this is the age where this things happen and all of that.

But as someone who had worked out six days a week for the prior decade, that did not make sense. I wasn't overweight. There was no injury, nothing. Anyway, I ended up with two back surgeries that year and I was disabled by the end of the year.

Could not go back to full time work. Because of back pain. Yes. Back pain. Basically, I was it wasn't just back pain, leg pain as well, because what it was, was as soon as I herniated within two weeks, I was dragging the left side of my body.

So my left leg was dragging when I walked. My left hip was dropping when I walked. And you know, we did. People walking. We know now that was really the MS It was the MS. Yes, we know that now.

But at that point they just attributed it to what they could see and we didn't really pull it out. Even I didn't put it together. It took another two years for me to realize that I was dealing with primary progressive MS And then came the real battle of getting a proper diagnosis so I could get treatment.

The initial neurologist was like, just kind of blew me off. And then I took myself to the MS center, where I met the kind of doctor who actually give me a diagnosis, even though at that point I didn't exactly meet McDonald's criteria.

So that's where my, my sir with M. S. began. And then did you start disease modifying treatment for when I was diagnosed then. I did, but that was the year later in 2016.

There was nothing for PPMS. So they did, you know, we did some, some steroid shots, you know, infusion and all that and that, you know, that just made me considering psychosis.

Yeah. So did it work? Yes. And so you were going steadily downhill. Oh, yeah. Just as we expect with primary progressive. MS Yes. you're probably not working anymore.

I was working four hours a day, but honestly speaking, I probably should not have been. But it's that, you know, it's that thing that doctors have where unless you can't get out of bed, you will.

You're going to work and never work. Yeah, you're going to work. and then did you ever take, any of the, disease modifying drugs for primary progressive?

I did in 2017. I did get started on, arquivos a few months after it got on the market. And that was because even though I was instituting lifestyle changes, I had found your work by this time, and I was doing what I could.

My downhill, you know, spiral was so fast I needed help. So I actually consider it part of my miracle that I was able to get on the at that point in time because it helped slow down the decline.

And then I could catch up with myself and the lifestyle changes that I knew to make. If I don't want to reinforce that for everyone who's listening, I want to be clear that you understand I'm not against DMT.

I just want to make clear that DMT will never be enough, that we have to do. Make your own decision about how DMT is fit for you. you know, if you have active disease, even I will encourage you to consider the DMT.

Yeah, but everyone should be doing diet and lifestyle. So. So you you took some alchemists. And I did. You had discovered my work. You're already really, working on diet and lifestyle.

What happens next, then? Well, what happened next was I did help slow down, and it helped me to implement more things. It helped me to research and do a lot of other stuff.

And I started to get better physically at least. I was getting better slowly. So I went from the transport chair and the scooter to a walker. For years I was doing the walker and then eventually the cane.

And then in the last few years I have not needed any mobility aid at all. I ain't going. I gotta stop that for a moment. Many people with primary progressive M. S.

who are in a transport chair get to a walker, get to a cane, get to walking without a cane. Not many, not many.

Progressive MS Diagnosis and Early Treatment

Oh, man. We'll give it back to you. I know and my now my cognitive decline though that continued to get worse even though my, my physical you know disability was getting better.

And eventually I did stop practicing medicine which was another blessing because honestly I was like the working injured for like seven years. I really should have just tough working and taking care of myself.

It was just the stubbornness and the, attachment to my identity as a doctor and not knowing what else I would do or could do, or how I could be useful in the world if I did something else.

But once I got through all the mind stuff and I did what I was supposed to do, I was then able to really dig in deeper and by this time I was already on.

Wahls Paleo Plus. So that was already helping greatly with the fatigue. So I started to swear. Why don't you tell everyone what was lost? They may not know.

Yes, that is the highest level of the Wahls protocol. And what it is, is you're really making sure you're eating the good fats. You're eating moderate protein.

You're still eating, you know, all of your vegetables and fruit, not too much fruit because you're trying to be in ketosis and you're practicing intermittent fasting and all of that too.

So it's it was really mostly berries and not a lot of other fruit just because of the, carb load from them. But, that was just magical for me. And some of it was like my brain opened up when I really started doing that.

And the fatigue also, went away with that. And I knew that I, I had hit the jackpot. I was onto something at that point, and I actually needed to stay on the Wahls paleo plus for years, for years.

But you know, when you're in the active healing phase, you do what you gotta do. Yeah, yeah. So so this is pretty exciting. you're walking without a walker.

You're walking without a cane. You're just walking. Now? Yeah, basically for quite a while now. And, something exciting, something else that's exciting happened recently.

Well, a lot of things have happened, but the most exciting thing that's happened this year is that I've been able to get off of the DMT octopus. So tell us about that.

Well, what happened was, I kind of knew that, you know, when I got done with the, comprehensive detox and I got done addressing, like, every single root cause that I could identify in myself, that there was a possibility that I would be able to get off of, upper levels.

But, what really happened to kind of push that, you know, to the forefront was that I developed mold colonization in my sinuses, and it was really very challenging to take care of it, to get rid of it.

And knowing that one of the, complications of Aquarius is that you can get chronic, you know, really bad chronic sinusitis. I suspected that that was what was happening and I couldn't heal or get rid of it and mount the immunity to get rid of the, of the mold in my sinuses because my immune system was being suppressed.

Now, the other part of it was that I changed, insurance companies, you know, medical insurance. And, I was no

longer eligible for the, manufacturer copay assistance for Aquarius.

And we know this medication is about $60,000 per, you know, per infusion that you get it, anything from 20 to 26 every 20 to 26 weeks. And at that point, I was getting it every 20 weeks because that's how frequently I needed it.

So basically, you know, I, I called up my doctor and I was like, you know what? These are the reasons why I want to come off of this. And we work together.

And, I was able to get off. My last infusion was supposed to be December, 15th. And, I'm still fine.

Lifestyle Changes and Functional Recovery

So I'm, you know, and I think, the other message I have, at least in my practices, if you want to get off the DMT, is you certainly want to work with your prescribing physician outline that you would like to have that as your goal, and then, jointly develop a plan to get there.

So that's also leaves me really curious. Is this the same neurologist that you had when you were in the transport chair? yes. It was the same neurologist.

He had seen me transform the whole time. And honestly, I think he also knew because he's seen the whole gamut of everything and he's done. Ms.. His whole life.

His father, you know, founded the Ms.. Center in Atlanta and all that. And he knew so he would always ask me, are we still doing Aquarius? Is it working?

So I and I always knew that he was willing to work with me. When I decided that I wanted to get off of it. And, it has this influence, how he is approaching his most patients now, is he talking more about diet and lifestyle or system?

I don't think he is. I don't know that he is, but what I like about him is that he's very supportive and he doesn't take your hope. Everything I do or did, I discussed with him and he was always very supportive.

It's like if I like if I like it, he loves it kind of thing. He never told people, you know, that's like snake oil or or whatever. That is worth a whole whole lot to have.

your treating neurologist be, the supportive. Yes. Yeah. No. We talked a little bit about your root causes. In your case, what do you think your root causes may have been?

my root causes were Candida. Then there was mold. there was mercury. I also had an infected root canal. I had trauma, and then I probably had a whole bunch of craters that I never actually tested for because for me, I didn't I wasn't one of those people that wanted to, be able to identify myself with all this different diagnosis or whatever.

That wasn't really important to me because I meet people who say, oh, I healed from 15 different, you know, chronic medical problems. And it's like a badge of honor.

I don't really care about that. I, I focused on making my terrain inhospitable for all the critters without necessarily needing to identify every single critter that was in there. So.

You know, for everyone who's listening, you know, at the time of Louis Pasteur, I think Beauchamp, there was this big debate what causes this disease?

Is it the bacteria? And Louis Pasteur said, it's the bacteria. And Beauchamp said, no, no, the bacteria everywhere it is the host and the terrain. and, for hundreds of years, we all believed in the critter, the bacteria, disease process.

and I think you and I agree that, yes, the bacteria have a role, but it's the terrain, the environmental factors surrounding the host that, drive disease.

So you focused on improving your terrain. What were some of the key things that you did for looking? the key things that I did, you know, in the. Of course, there's always the backbone of the nutrition, the exercise, the lifestyle and all that.

But, you know, I, I addressed all of this things that I listed. Basically, I went and knocked out each thing. You know, I had my root canal out. I took out all the mercury in my mouth.

And that was one thing that I did test for, because, you know, when you're doing all those dental things that cost a lot of money, you actually want to know that it's a factor for you.

Even though I knew that I had silver fillings from when I was little, but I did do an TMA, that was one of the tests that I did. So we can explain what that is.

Yeah, that's the hair tissue mineral analysis. And it tells you if you have like a problem with heavy metals and stuff like that in your, in your system and it's just, you know, you just get a sample of hair, it's really easy and relatively inexpensive.

So I didn't do that. I also did this do microbiome, you know, according to I used one of those companies that you recommended in the Wells protocol. Right. Yeah. Bible. Right here.

Yes, yes. So yes, because that that was important because that really is the basis of everything. And the seed of your immunity is the gut. So to fix my God, I needed some information so that I did do.

And it also confirmed what I already knew that I did. You know, I was overrun with Candida, which I've been dealing with Candida since I was a teenager, so there was no surprise there.

Yeah. You know, and for, for, again, you listeners clues that Candida may have become a problem is early antibiotics before particularly before the age of, three years of age, frequent antibiotics as a child, long antibiotic use, as an adult, or a really high carb diet.

And most people eating a westernized American diet or a Western European diet high in added sugars, in additional, processed flour based cereals, pastas, breads were more likely to have an overgrowth of those, sugar loving use.

and so that was probably took you, quite a while to reduce your, candida overload. Yes. And the, the also, paleo plus really helped with that because if you're not eating a lot of carb and you're not, you know, taking any processed or artificial sugars and stuff, it really does help.

And it was really in line with a lot of the Candida diets out there. And, over time, I was able to, you know, get control over the, the, excess candida in my body because it's not something you get rid of.

You naturally have it. It's just the fact that you have an excess of it that is a problem. And it's able to change your genes, you know, to where it's not doing what it's supposed to do. And, I believe that's what happened with me.

Coming Off DMT and Root Cause Work

You know, I think that's part of why so many people find a ketogenic diet to be really helpful for anxiety, for depression, for, more serious mental health issues and for people who have a neurologic, disorder, whether it is Parkinson's, Alzheimer's, or in our case, multiple sclerosis.

so you mentioned that you are, none travel medicine physician or are you still an internal medicine physician, but you're not practicing traditional internal medicine.

And of course, neither am I. I haven't done that in many years. what is it that you're doing now? Well, right now I have an online program called, Ms..

Mastery. And what I'm doing is, teaching women with M. S. how to improve their quality of life, basically by, you know, decrease in their daily symptoms and their flares and, just how to have better functioning and hopefully reverse, you know, their, reverse the course of M. S.

in their bodies and their disabilities and stuff get similar results to what I got and what Doctor Wallace got into. Are these, for people with progressive Ms..

You know, It's. A secondary progressive or does it really not matter? We don't exclude people with remedying relapsing because evidently they're just going to have to do less than the people with progressive.

But, what I'm noticing is the women who are drawn to me are mostly progressive. Ms.. Especially PMS have a bunch of Ms.. Ladies. Well, you right, it makes sense to me because there's, so few options for people with primary progressive Ms.

or secondary progressive. I was there there. We have drugs that do a great job of turning off the relapses, but none of the drugs stop the progression.

No, none of the drugs stop the brain volume loss, none of the drugs teach people how to restore, the ability to repair the while. No, no, that's the stuff that you and I talk about.

Okay? There are things that we could be doing. and so in your online program, are people all just meeting via zoom, or are they, these are prerecorded, courses, modules?

What's what's the usual process? It's actually a combination. It's a 12 week program. And, there there are recorded modules. It's six main modules played out through the 12 weeks.

But once a week we meet on zoom every Wednesday afternoon, and we do the Q and A for the module. you know that we don't. We don't. Grow the week. And I'm also planning to do a membership, a backhand membership, because people do need help with implementing even after the learn all the stuff, because it's just so much stuff.

And it's, so helpful to have that, peer to peer conversation. You. When when I was running our therapeutic lifestyle clinic at the VA, what I learned, from my veterans, my fellow, my patients, was there's something magical about the patients talking to each other.

My clinical staff and I could be discussing the same concepts, but it lands very differently when it's another patient with a chronic disease. Yes, it's telling their story in offering encouragement like, yeah.

I was like, wow. groups are incredibly powerful. So again, anyone who's listening, the more you can find a peer group that you can interact with to talk about your experience as you're implementing a better, it doesn't matter whether it's a huge ethnic diet or even a mediterranean diet or a vaccine, that that you have another person that you can talk to about your experiences and health problems. All.

Yes. And I have noticed that in our weekly sessions that, you know, it actually really helps when other people in the program jump on and give their own tips and everything so it doesn't look like, oh, it's just Doctor Phil, I could just telling us what to do.

Well, she's like, you know, I'm like a unicorn or whatever, but no, I'm not a unicorn. When you have other people telling you, you know what, I can do this, I can do that, or.

Yes, that's what she just said. It's true. It happened to me that just really helps and solidifies everything and ends up feeling like we just had a support session every single week.

It is, super helpful. Now there's another, I think that I'd like to talk about is your experience and what you've seen for, the African-American community and, communities, because most of the research has been done on Caucasians, we don't have as much, as rich of a research experience with the African-American community.

And, and I have the sense that it may be harder for the African-American community to get diagnosed. So I'm going to be curious about your observations and your experience.

Yeah, my observations as well as, you know, observations from the few papers that have been published show that there's less access, diagnosis is later, which some of that is because when you don't have enough research on a certain demographic, things may show up differently in them that are not recognized.

Now, people are aware of the fact that you know that, for example, African-American women seem to be at the greatest risk for developing M. S. in the United States from that Kaiser study that they did in California a few years back. But, before all of that came to the forefront, people didn't have this information.

So and another thing is, by the time an African-American gets diagnosed with usually progressed and, It's also the they have probably passed the relapsing remitting phase in the progressive phase.

Oh, yeah. Yeah. So they've been diagnosed in their 40s and older. Yes.

MS Mastery Program and Community Support

Whereas the white women and men are diagnosed in their 20s. Yeah. More likely. Yeah. Yes. So by the time you know it's it's you have a diagnosis, you're already disabled.

And then it appears African-Americans also progressed faster and just have a more disabling course of, of Ms.. And even with medications, there's so many medications and all that.

But they're really still trying to figure out what medications work best for our demographic. just so many things. Because if you don't have the research, you just simply do not know.

You don't have enough information. you know, I also have the sense and but, you know, correct me if I'm wrong that, people with primary progressive Ms.

are more likely to have poorly diagnosed pain. They've had pain for years with a variety of diagnoses for that pain. and the the pain treatments don't respond.

Well, and, another pain syndrome develops. Another pain syndrome develops. And then eventually someone, considers and evaluates the person for, primary progressive MS That is true.

That's certainly what, happened with me my whole life. I just knew that the only medical problems I seem to have were physical problems. You know, it was like joints and bone.

And it was, you know, I didn't have any any other problems except just physical stuff. So again, the primary progressive, were often diagnosed in our 40s, secondary progressive, diagnosed in her 40s.

And for those people who are diagnosed with relapsing remitting the later in life that you're diagnosed, the more rapidly you convert into the progressive phase of the illness.

and in the progressive phase of the illness, the DMT, which are, which are super effective at tearing off, enhancing lesions, because you're really having enhancing lesions after the age of 45.

That's very, very rare. It is mostly progression shrinking, brain shrinking spinal cord. And the DMT don't do much for that. Exactly. You're you're really right.

In fact, my MRI's were always what my doctor called underwhelming. in fact, one of the reasons why I didn't meet criteria initially it was because they barely saw any lesions on my brain. MRI could you might as well be just, migraines from, you know, when I had, there.

Yeah, yeah. And again, that's because the degeneration component is more. Pronounced than the information. Than the inflammation. Component. Yes, yes.

And he also said that, you know, at best, the MRI's that they have now probably see maybe 50% of the lesions that are present, they're not even seeing everything.

They're just seeing some of it. absolutely true. Now, because I do research, I get to have a much more powerful magnet. and so we're able to do a more detailed look than your clinical neurologist can do with their clinical MRI.

and, we're using some special sequences, so we'll see. what's happening with the myelin? yeah. One of the questions we'll be looking at is so is my own, you know, being repaired, as we go. So, that that will be fun to see.

fun to. That's the case, in, but I won't be able to talk about that until 2027. And so we have a few more years, until we know. I'll be right here. And I'm waiting for those progressive studies that you've been working on.

Well, you know, I keep writing grants. and so were we did not get funded for our progressive MS study, we're trying another round of studies, to talk about how to make it, more safe to come off the DMTs, and so we're we're, having a proposal, where we prime everyone with diet and lifestyle, and then randomized them to either stay on the DMT or go off the DMT.

so we're sending those grants in, we'll get scored and, so we we made changes to our grant based on the last feedback.

MS in African-American Patients and Research

And usually that's what happens is you you submit it, you get feedback, you make some edits, you resubmit. And so we'll see what, what they think about resubmission.

Wonderful. So we are hopeful I can't wait. We are so, so excited. So, can you tell us where to find you, your Instagram, your website, and. My website is, folaketaylormd.com.

That's F as in Frank L as in orange L as in Larry A as in apple K as in kite E as in egg and then Taylor T A Y L O R. So Sally oh I'm sorry just.com I'm sorry I was I was trying to spell my other email address or whatever.

So just put folaketaylormd.com Okay. Perfect. in that's for your website. Do you have an Instagram? I. Have an Instagram. It's, @folaketaylormd as well. So.

Okay, that's pretty much what I am most places, folaketaylormd okay. Well, this is perfect. I love what you were doing. I love that your your story gives hope to the, thousands of people with primary progressive MSYes.

Thank you so much. Always nice to have this conversation with you.