A Freedom To Know Wellness Podcast Transcription S1: Ep 6

Managing Multiple Sclerosis with Fibromyalgia with guest, Dale Nevison

[Prelude] Dale: "It couldn't function with it at all and somebody brought me a full pan a pop and I rested it on my leg and it was so strange because it felt like pain like shards of glass and what I know now is the part of the spinal cord that carries the messages of pain there was a lesion there"

0:00:00] FTKW: Welcome to Freedom to Know Wellness, a disability advocacy platform to hold space and give a voice to those with complex medical and chronic pain conditions, female reproductive challenges and miscarriages, and address other disability related topics, including how these experiences affect one's mental health.

Our goal at Freedom to Know Wellness is to connect and bridge the gap between patients and the medical and holistic community in which they seek treatment. I am your host, Michelle Samuels. Now before we start, please remember to subscribe to the Freedom to Know Wellness channel @FTKWellness to catch all of our content.

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Multiple sclerosis is a chronic disease that can commence between ages 20 to 40. It attacks the body central nervous system by destroying the myelin sheath, a tissue that surrounds and protects the nerve fibers, brain and spinal cord.

As the myelin sheath is destroyed, scar tissue forms. This scar tissue is called sclerosis, also known as plaques or lesions. When these nerves are damaged, it hinders the conduct of electrical impulses to and from the brain.

There are several side effects to this condition, varying in individuals from mild to severe. These are some of the many common symptoms. Optic neuritis. Blurred or double vision. Red green color distortion. Difficulty walking. An abnormal feeling or pain such as numbness, burning sensation to cold, prickling or pins and needles.

[00:02:00] This is also known as paresthesia.

Other common symptoms are:

slurred speech, (speech problems), loss of sensations, muscle weakness, spasmatic. And more.

Managing multiple sclerosis as a sole condition is difficult enough, with its vast debilitating symptoms, but when compounded with other chronic pain and complex medical conditions, it doesn't make the experience any easier.

Today on Freedom To Know Wellness, I am speaking with Dale Nevison and her journey managing a severe case of multiple sclerosis and the chronic pain condition fibromyalgia. Let's jump into this interview to learn all about her story.

Today on Freedom to Know Wellness, the podcast, I would like to introduce, one of my past educators-- actually, a mother, partner, but with the topic we are addressing today, a multiple sclerosis and fibromyalgia warrior. Her name is Dale Nevison.

[00:03:00] Welcome Dale to the Freedom to Know Wellness podcast.

How are you doing today?

[00:03:03] Dale: I'm doing great. It's so wonderful to see you, Michelle.

[00:03:06] FTKW: Good to see you too. So, tell our listeners a little bit about yourself.

[00:03:10] Dale: Well, let's see. I just turned 60 this year. I've had MS for close to 24 years.

[00:03:19] FTKW: Okay.

[00:03:20] Dale: I used to teach in the Durham, Board of Education, I taught visual arts– I was head of visual arts at Pine Ridge Secondary.

(Both chuckle) unfortunately, MS did end my career rather early. I think I was 12 years into teaching and, had to go on, disability leave very early. But I have two wonderful kids, one who's moved to North Carolina, one who still lives with us.

[00:03:47] FTKW: Oh wow, nice.

[00:03:48] Dale: We still live here in Richmond Hill and, we're all muddling along and getting through this.

[00:03:54] FTKW: So you mentioned that it was about, 12 years into your teaching, that you were

[00:04:00] diagnosed with multiple sclerosis. Were you having any symptoms prior to your diagnosis or like what was the-- what led up to your diagnosis is what I'm trying to say.

[00:04:09] Dale: Well, it came on rather suddenly. It was one July, I just finished tidying up my classroom. I was moving schools. I was actually going to be moving to a new school in the fall. It was a stressful time. There was a lot of labour disruption. It was a seriously stressful- stressful year teaching. And I was at the hairdresser one day and vertigo hit me.

And I got home and my legs just felt kind of heavy. And I went to the ER and they just kind of rolled their eyes and said, ah, you're probably suffering from stress. I said, No, it's July. School ended. (Michelle chuckles) Well, this is not a stressful time now.

[00:04:52] FTKW: Right, right.

[00:04:52] Dale: It started progressing over a few days and I ended up back in the ER.

Because my legs, I lost feeling, and they were really heavy and the dizziness was absolutely-- I couldn't function with it at all. And somebody brought me a full can of pop, and I rested it on my leg, and it was so strange because it felt like pain, like shards of glass. And what I know now is the part of the spinal cord that carries the messages of pain, there was a lesion there.

And so I was only registering cold as pain, not as cold. I couldn't feel cold. And they kind of rolled their eyes at me, sent me home. They probably thought I was crazy, right? And I ended up in my GP's office because I had trouble the next day urinating. And I dragged myself up the stairs to his office and he called me back and called the doctors at the ER and said, get an MRI done right away.

Something's wrong. Her reflexes, everything went very fast, kind of an unusual presentation, right? It usually doesn't come on. And within my 12 hours, I was completely paralyzed from the chest down.

[00:06:09] FTKW: Oh my gosh. Oh, that's rapid.

[00:06:13] Dale: Oh, I was in a panic because I had just resigned from the school board because I had taken a position in York, and I was afraid because I would be on probation for two years and everything where with the other board and my resignation had already ended. Anyway, it was just an absolute chaos.

They admitted me. They gave me a ton of SOLU-MEDROL and told me I'd probably recover. It still wasn't an MS diagnosis at that stage. It was called transverse myelitis. So, they thought, okay, she'll get the SOLU-MEDROL and recover. I didn't fully. I ended up at the Durham board, thankfully they

were very compassionate and they-- they took back my resignation and accepted me back so that my benefits would stay because I never...

[00:07:08] FTKW: Okay

[00:07:10] Dale: Yeah, luckily, I've had some really strong support in those years, got me through that.

And, so yeah, I never was able to return to school. The good news is, though, that after about nine months, I started to feel feeling in my feet again.

[00:07:30] FTKW: Okay.

[00:07:31] Dale: And from that point until now, I'm still walking.

[00:07:36] FTKW: That's very good- that's very good news. Very good to hear.

[00:07:40] Dale: The damage accumulates, you know, over time.

[00:07:43] FTKW: Right.

[00:07:44] Dale: Sometimes when you get hit with these flares, if you can get it treated right away if I got on SOLU-MEDROL right away...

[00:07:52] FTKW: Mm-Hmm.

[00:07:53] Dale: I would be able to return sometimes to baseline. If the damage is allowed to fester, sometimes it won't go back to baseline like that. So that's the story of how the diagnosis kind of happened.

[00:08:07] FTKW: Oh my gosh.

[00:08:09] Dale: Yeah, it was pretty, it didn't fit a textbook, as these things often don't, and by the time it was, they got me to a neurologist down at St. Mike's, it was about six months, and he thought, oh, it's just, whatever it is, it's benign, you're going to be fine...

[00:08:26] FTKW: Mmhmm.

[00:08:28] Dale: And then that January, I was hit with another major flare that landed me in down there, (St. Mike's) and it was a young resident, who just said, you know, look, I think we need to run an MRI again.

And he goes, yeah, there's a second lesion. Now you fit the diagnosis criteria.

[00:08:47] FTKW: My Goodness.

[00:08:49] Dale: In the middle of an item at St. Mike's and this sweet nurse, a nurse who obviously been at St. Mike's for a long, long time because she was a nun and St. Mike's, I haven't seen too many nuns at St. Mike's since, but she wrapped me up and she did old-time nursing and I just thought it's going to be okay.

[00:09:10] FTKW: Yes.

[00:09:11] Dale: Yeah.

[00:09:12] FTKW: You know, sorry, you mentioned about that nun and St. Mike's hospital that I usually go to and I remember there's a nun there. I had to go to Emerge, and there was this nun there, and I remember thinking, oh, wow. And she was very nice, and I'm thinking, could that be the same nun?

But I guess, you know, different, individuals who are from, those denominations, being nuns, or practicing in that way, do, give back in the hospital vicinity. So, but wow, wow, that's, that's intense, very rapid... and it's funny how it took, an intern to be able to really advocate and push to be able to say, hey, you know what, this is not something that's short term.

It's actually something that is happening and it's long term and they advocated for you to be able to have that other MRI... for your diagnosis or completion of your diagnosis.

[00:10:01] Dale: It, I think because he had the time.

[00:10:04] FTKW: Mm. Mm hmm.

[00:10:06] Dale: Because he was in school, and he had a presentation to do the next day. So, I became the presentation, which was me.

So, he got to play with my eyes. I developed double vision. That's like pretty diagnostic of MS because one eye was completely off it. There was clearly something going on. He then presented it the next day. And that's how the diagnosis happened, and I think the neuro that I originally saw came in, it was Easter Monday... Easter Sunday, and he, actually came in and sat with me I was surprised that he came in.

So, he was quite apologetic that he missed it and kind of been dismissive, so he took over my care from that point on. And Abby, the young resident was, in to visit lots and I still remember his first name. That's how central he kind of was.

[00:11:02] FTKW: Goodness, but I'm glad that the doctor at least was willing to come in and, you know, to address the fact that they missed this.

This was an error on his part and that he's willing to acknowledge that. You know, but I hope he received the best care starting from then.

[00:11:17] Dale: The care in the early years.

[00:11:19] FTKW: Mm hmm.

[00:11:21] Dale: Back to 1999, 2000. The access to care was very, very different than it's now.

[00:11:29] FTKW: Mm-Hmm.

[00:11:29] Dale: And the MS Clinic, then it was in a different location in the building.

It was the old part of St. Mike's. It almost looked like the movie out of The Elephant Man. And I was in this old room with old beds. But the care was excellent, and the doctor, the neurologist at the time, he's since retired, was very aggressive from the start. In the fourth year, he put me on a chemotherapy that just knocked everything back.

I was on chemo for four years, a drug called Novantrone.

[00:12:05] FTKW: Okay, and what did it do, you said?

[00:12:07] Dale: It knocked my immune system out completely and put me into remission for four years, completely into remission. But you can only stay on it for that amount of time because it's very toxic on the heart.

[00:12:23] FTKW: Mmhmm.

[00:12:23] Dale: So, I was lucky to get on that drug.

He had put me on the list for the trial for the stem cell transplant trials were just starting and then they lost patient seven died in the trial in Ottawa from, liver failure, it would've meant having to stay in hospital for three to four months in complete isolation because... it– the procedure completely, eliminates your immune system and you have to start building up again with vaccines and everything. And I had really young children and my husband was self-employed trying to hold down the business where he was working six seven days a week. It was just it wasn't a possibility and--and then they lost patient seven and so I- I was really leery about the risk versus the benefit at that point.

[00:13:26] FTKW: So, did you continue with the trial or did you decide to extract yourself from it?

[00:13:30] Dale: I didn't continue.

[00:13:31] FTKW: Yeah, yeah. No, that's, that is scary because you have dependence. It's not like it's just you and you say, okay, I'm just going to try it. But you have your husband and you have your children.... yeah, that's not a risk that you're willing to take at all.

[00:13:41] Dale: Oh, no, no, they were 10 and 5, sorry, 5 and, yeah, 5 and 10.

[00:13:48] FTKW: So, how far did you get into the trial? Did you see any benefits and- any benefits at least during the time where you're, when you were in the trial?

[00:13:57] Dale: I was only just starting the process of considering it where they were the neurologist was explaining the procedure.

We were trying to make a decision to begin it. And one of the things at the time that he was very cognizant about was that the consent, for it required somebody to be, able to understand.

[00:14:22] FTKW: Mmhmm.

[00:14:23] Dale: And so, at that time, at least cognitively, I was a lot better off than I am now, and I was able to understand how the data worked and what it meant.

And we both decided, though, that after patient seven died, that with the kids at home, this wasn't a good idea.

[00:14:43] FTKW: So, with where you're at now, your mobile, are you using any devices at all?

[00:14:48] Dale: Yeah, I flip through devices sometimes. So, in the house I can kind of wall walk and, you know, stumble around. I use a cane sometimes, but outdoors more and more now I'm using a Rollator.

And I do have a manual chair now that, I can go longer distances. I haven't really been too far since COVID, you know, needed to be out that far, I've been able to manage with the Rollator for the most part. But I'm back using the cane though, getting to physio, so...

[00:15:23] FTKW: Good.

[00:15:24] Dale: It goes back and forth, you know, the stuff it's like, it's like having coats in a closet.

And when you need the heavy coat, you put it on if it's really cold and snowy, and you can put the rain jacket on when you just need a little bit of shelter. (Michelle chuckles)

[00:15:38] FTKW: No, it's true. And the the mobility wheelchair. Or is it the like a scooter that you're using?

[00:15:47] Dale: I had a scooter originally. The scooter, I don't use anymore. I'm probably going to sell it because it requires a fair bit of balance to get on and off.

[00:15:58] FTKW: Yes.

[00:15:59] Dale: It's– it's hard to get into a vehicle without a lift. But I don't have the balance. And after taking out a couple of displays and stores. (Dale chuckles) Trying to reach up to get things off cans and hitting the throttle and you know, just about taking out other customers and things It's really not a safe option.

[00:16:21] FTKW: Yes.

[00:16:22] Dale: And also not good for posture as you lean forward and it's so not great long term. The manual chair is custom fitted I sit better, and the seating is better...

[00:16:37] FTKW: And it keeps you more stable.

[00:16:39] Dale: Yeah. That keeps me from sliding over or, you know, keeps, keeps me upright and as much as possible, sometimes I just sit in it and the desk as well.

It's that comfortable with the seating.

[00:16:53] FTKW: Actually, I've been told that from quite a few of the people that I know that use them, they say it- the back support-- this one lady said, Oh, I could even sleep in it. I said, really? She's like, yes, it's so comfortable compared to when she had to use the scooter, so... I'm glad you have that because you need the benefits of whatever type of devices that can help you to find freedom,

support, et cetera.

[00:17:13] Dale: And I mean, not to be embarrassed of that-- that, you know, that you need to use it and it allows you to, you know, find joy in days and getting out there. That's the main thing.

[00:17:29] FTKW: Mmhmm. That's true. That is true. So, you also mentioned, to me at least, and I'll let my listeners know, you did mention that you also have fibromyalgia.

Now, was this a later diagnosis or was the diagnosis went hand in hand?

[00:17:42] Dale: Yeah, it was a much later diagnosis, although looking back, it may have actually preceded the MS, because I've had migraines since my teens, bad migraines, and sometimes that can go along with it, but...

[00:17:56] FTKW: Mm hmm.

[00:17:57] Dale: Ended up down at the Rum-- Rumsey Center for Physiotherapy.

And they specialize in MS therapy there. And there was a physiatrist, which is different than a therapist...

[00:18:11] FTKW: Mm-Hmm.

[00:18:12] Dale: Physiotherapist. They're actually board-certified with neurology. And it... she was a medical doctor, Dr. Bruno, really brilliant physio-- physiatrist who, when she was doing my exam, my neuro exam, noticed I was having, like, a lot of pain when I was asked to push my legs and she'd have my hand against her hand against my shin.

It would elicit, like, a lot of pain that should have been. But then she got curious and started looking for all the pressure points and went, oh, okay, well, that explains a lot.

[00:18:47] FTKW: Yes.

[00:18:47] Dale: Fibromyalgia. So, it's hard to distinguish what part of the pain is from fibromyalgia and what's from MS.

[00:18:59] FTKW: Please note the feeling of pain when touching something cold, as Dale mentioned, is also felt with fibromyalgia. So, it could be due to either one of these conditions or both.

But with MS it's more severe.

[00:19:12] Dale: yeah, I can usually tell now, the difference between what's what just with experience.

[00:19:21] FTKW: Mm hmm. Mm hmm. You said Dr. Bruno, is she also working, has she ever, or is she currently working that you know of at Toronto General Hospital?

[00:19:31] Dale: She could be. She could be. I know that the Rum... Toronto Physiotherapy is the Hospital, it's I think next to Mount Sinai.

[00:19:44] FTKW: Oh, the Toronto Rehab. Yes.

[00:19:46] Dale: Yeah, so she's out of Toronto Rehab, but I saw her at the centre that was on, what's that, Bayview, near Sunnybrook Hospital, there's a centre there.

She was doing my rehab care for many years, and I went into a program at the Rumsey where I go 2 -3 days a week.

[00:20:09] FTKW: Mm hmm. It could have been Sunnybrook. So, I've been made aware of her. So, I couldn't remember if it was Toronto General Hospital or if it was Sunnybrook, but I have been made aware of her and I heard she's excellent.

[00:20:19] Dale: Absolutely outstanding.

[00:20:21] FTKW: Yes, it's, it's funny because for a lot of people who have fibromyalgia, you go through, you know, the barrage of tests to confirm. First of all to rule out, if you have MS, if you have Lupus, there was another one that they tested you for. And then when all else fails and they realize, okay, you have all the trigger points, you have all those other things and it’s fibromyalgia. But to have both, that is very difficult.

[00:20:47] Dale: I've heard from other MS patients that I know several of them have that diagnosis as well. And also I find that the pain from the fibromyalgia exceeds the pain that they're usually getting from the MS.

[00:21:03] FTKW: Yeah, yeah. Whenever I talk to my other MS friends that don't have fibromyalgia and I talk about my pain, they're like, why is it like that all the time?

And I'm like, I don't know. You know, so when you mentioned that you have both, I was like, oh, dear God. (Chuckle) That is a killer!

[00:21:20] Dale: Yeah, and you know, my mom also has fibromyalgia. Yeah, so she was diagnosed years ago with chronic fatigue syndrome and then fibromyalgia and she, they put her on like amitriptyline years ago.

It was awful. She really suffered with that a lot and that was years before. I got MS. But I think they said at the time her Epstein Barr titer was very high.

[00:21:53] FTKW: Yes.

[00:21:54] Dale: She had obviously had reactivated or something. And she, when she was pregnant with me, she had mono. So I often wonder, you know, there's like a researcher interested on how that happened.

So if she developed, you know, fibro and CFS and you know, in a short time frame for me starting to develop MS, what's the connection with the Epstein Barr virus, that EBV virus that they know is probably implicated in MS now?

[00:22:29] FTKW: This is something I– I will be addressing in the blog and as well as, individual podcasts, but Epstein Barr, Lyme disease are very common for creating fibromyalgia. Fibromyalgia, chronic fatigue, you know, they go hand in hand and one of the things when I was first diagnosed, I remember it was a whole lot of us that were in this clinic going for trigger point injections, seeing this rheumatologist, seeing the physiatrist and there was this woman that was there with her son and for me, I was 25 and my mom was with me and I'm seeing her son and he's a teenager.

And so I asked her and she goes, she has fibromyalgia and now her son has fibromyalgia. And we're realizing that there is a hereditary effect with fibromyalgia to pass it down to the children. And that, that really shook me.

And when you mentioned that she had Epstein Barr during her pregnancy, it's, it's strongly connected. That's very connected. If there's any strong evidence that I've ever heard, it's right here. Oh, wow.

[00:23:41] Dale: Yeah.

[00:23:42] FTKW: Yeah. And it's funny because that's one of the things they said, okay, well, you know, do you have any other family members that has MS?

And I have other family members that have MS. And they realize that there's all that connection, genetically, that it can affect people in certain ways. My other aunt had myasthenia gravis. And the way my body was acting up, they were wondering, oh, is it that? That was the other thing I was trying to remember.

If it's that and thank God, it wasn't. But it's, it seems like there's a connection within those types of autoimmune-arthritic diseases, et cetera. Oh, wow. Well, thank you for sharing that.

[00:24:19] Dale: I mean, they're making like links with it, too, to Alzheimer's even, right?

[00:24:23] FTKW: I didn't know that.

[00:24:25] Dale: Alzymers in the last couple years as well.

[00:24:28] FTKW: Well, it makes sense with the with the brain fog that we go through.

[00:24:33] Dale: Oh yeah, a brain fog. Try to explain that to somebody, right? It's like, like trying to think through wet cement.

[00:24:42] FTKW: Yes, yes, it is, it is. I explained that I said it's literally like a thick fog and you're trying to pinpoint the words and I'm trying to separate it.

And I'm like, I know it's there and it's just everything just gets combined and then you can't see what you're trying to say. And every one goes through some type of fog, as human beings, we do. But then it's when it gets extreme, and as you said, we're like, we're trying to explain, we know the general type that, okay, people go through general fog, but when it's extreme, it's like, it's not the same.

And it makes, it makes you question your intelligence. You know, it's yeah, just cognitive, like I remember trying to think of person's names and I'm going through the alphabet trying to see if I can remember the first letter. Maybe I can remember the rest of the word.

[00:25:29] Dale: I just have invented language, and my family gets it, right?

Like, instead of the spatula, I'll go with the flippy, flippy thing for the frying pan. (Both chuckle) They all speak the same language now because they just know.

[00:25:45] FTKW: Yeah, they know what you mean. I used to run this soup kitchen, and I would tell the-- the volunteers that are there, and I would tell them, I said, listen.

I said, I may be, I may mean the frying pan, but I may say the refrigerator, just look where I'm pointing to, then you know what I'm saying. And they're like, okay, and after a while they started catching on, they're like, what? And I'm like, no, no, that, that, and they're like, oh, okay, yes, we get what you're saying.

[00:26:11] Dale: I figured out a new way of communicating like the nerve pathways just have to reroute around. Sure. And come back, right?

[00:26:20] FTKW: Yeah, exactly, exactly. So you mentioned some of the medications you listed some of the medications, what current medications that you're on and which ones were you taking before and you found that didn't have the best effects and then your medications probably changed to something better.

[00:26:37] Dale: The, development of science with MS medications has really changed. Quite a bit over the last 23, 24 years. I'm currently on a drug called Mayzent, which for me is a last kind of resort one, run out of medications. So Mayzent or Siponimod, is related to another drug called Gilenya. And it… what does it attack?

I'm trying to think. One of the cells, T cells? B cells? I can't remember. They all affect like, different cells in the immune system, but this one dampens down my lymph Lymphocyte count which is almost non-existent at this point. So, it's like a chemo drug. So, I have no immune system, but it means that it's-- it's not actively attacking, you know, central nervous system tissue at this point.

My MRI is stable for the first time in two years, but it's not likely to improve anything. It's just preventing some ongoing damage. Because in Jan-- January of the year, it was COVID, that would have been, it would have been a year like 2021. I had another massive attack that caused dystonia, it looked almost like seizures.

And so, they put me on that to dampen down my immune system. Things seem to have calmed down I'm not having back-to-back-to-back attacks.

[00:28:12] FTKW: So, with the seizures, did they diagnose it as a dystonia, or did they diagnose it as something else?

[00:28:19] **Dale:** It's a weird type of, they call it dystonic posturing. So, it looked like a seizure when it happened to be.

Five to ten minutes, my right arm, it started with my hand, and then eventually over a week or two, it started to be the whole arm, it would curl up tight, and then it started to be the right leg, and it would just, it was, extremely painful, very short lived, it would just be like 30 seconds, and then would release, and then everything would be fine.

[00:28:54] FTKW: Mm hmm.

[00:28:55] **Dale:** But I wasn't tired after. I didn't have like a post ictal response *(period of a seizure)*, which is more typical of seizures. so finally the neurologist thought, okay, they'll put me on gabapentin for a while. And I don't know whether the gabapentin actually did anything, but eventually they stopped. It took like six, seven weeks of it.

But eventually my, the right side of my face also, like grimace, and it would hurt so much that I would, like, when, when it happened, my hand would curl, it would actually, like, cut, my fingernails would cut the palm of my hand.

[00:29:33] FTKW: It would get stuck, yeah.

[00:29:35] Dale: (Inaudible) Open. It was such a strange, strange thing. Yeah, those dystonia episodes were extremely unpleasant.

That was incredibly painful.

[00:29:51] FTKW: I'm so sorry. You mentioned that they had put you on the gabapentin. So do they give, they were never giving that to you beforehand to help with the fibromyalgia pain at all?

[00:30:04] Dale: Dr. Bruno did have me. I went through a period where I was having a lot of problems with my tailbone area and sitting with pain.

The pain it was so bad. I was, like in tears, nonstop, it was really nasty nerve pain, and she put me into the mindfulness program at Rumsey and started me on the gabapentin, and took a while, but it did help.

[00:30:36] FTKW: Okay, good to know, good to know. And the Mindfulness Based Stress Reduction Program, how did you find it and do you still practice that now?

[00:30:46] Dale: So, it was a group session, so there were about 15 of us from everything from head injury patients to fibromyalgia to MS and I think we had a couple of Parkinson's patients as well. And it was great because first of all having that group of other people and go, oh, yeah. Oh, yeah, that happens to me. Yeah, yeah and in a group having the focus kind of change to like a group...

it's-- it's like just a weird connection when you're all in that space and you're all very mindful of everyone's breaths even.

[00:31:33] FTKW: Mm-hmm.

[00:31:34] Dale: And having to kind of find that calm center. It was really helpful and yeah, I do practice it not on a daily basis necessarily. Usually at nighttime, I'll often run through an exercise.

[00:31:50] FTKW: So that was the other thing I was going to ask you. How is your sleep and do you or are you able to sleep consistently through the-- throughout the night?

[00:31:56] Dale: Better now, better now. (Inaudible) I am on Remeron, which is or mirtazapine, just a very small dose, I think 7. 5 milligrams that helps me fall asleep and stay asleep at least until six, seven in the morning.

So...

[00:32:18] FTKW: So you had no side effects to the Remeron?

[00:32:21] Dale: No, not really. It's one of the better ones because I don't feel dopey in the morning on it. I do keep the rollator by my bed if I have to get up to the washroom because it can make me a little bit wonky.

[00:32:35] FTKW: Mm-hmm.

[00:32:37] Dale: It's sedating for sure.

[00:32:38] FTKW: Yes, yes, it is, it is. I've been on that one before.

I came off of it because I had a weird side effect, so I'm glad that works for you because sleep is important for the brain and the body to heal.

[00:32:49] Dale: Yeah, for sure.

[00:32:50] FTKW: Yes. So, you did mention that you do some type of exercise programs. Are you still going to Rumsey or where are you doing that at this present time?

[00:32:59] Dale: Oh, I'm doing it through a private program now. In Thornhill, it's called Neurocore and it's just an absolutely fantastic.

Place that, they've created there. So, it's a neurophysio center (*Neurocore Physiotherapy and Pilates Centre)*. So, they have, they specialize in neurological physiotherapy. So...

[00:33:21] FTKW: Really?

[00:33:22] Dale: It's absolutely outstanding. And they've created a wonderful community in there. So, there's not, they have some individual treatment rooms that they use for massage and stuff like that.

But it's almost more like big, very bright, open, gym spaces. So you see other people working at it. At first, I thought I don't know. But you know what? It becomes a big community. So, everybody's joking around, laughing around. You get to know kind of everybody. And the-- the physiotherapists are so dedicated.

And so specialized.

[00:34:00] FTKW: Mmm.

[00:34:01] Dale: That when I went to physiotherapy before, that often they specialize in sports physiotherapy or car accidents or whatever or golf injuries and with any kind of neurological injury, they have to know when to push and when to not fatigue you, and what kind of exercises, what to do with gait and balance, and they're just, they're outstanding.

[00:34:33] FTKW: Wonderful.

[00:34:33] Dale: Absolutely.

[00:34:34] FTKW: So is there, are there any specific techniques that they use, or they just have a specific set structured type of physiotherapy program that is geared to anyone with any type of neurological, condition or one that's specific for MS, for functional neurological disorder, et cetera?

[00:34:54] Dale: Very individualized.

So, they have (inaudible) patients in there they have Parkinson's, a lot of MS patients…

[00:35:02] FTKW: Mm-hmm

[00:35:03] Dale: (Inaudible) ...spinal cord, injury people there. So, there's a lot of people in wheelchairs, the equipment– there's adaptive equipment in there You know, can be used, you know, different stages of mobility. So sometimes I'll be seated but working on a ski machine with my arms.

They have a treadmill with a harness. They have very specialized equipment. And Ali, the assistant that I see also runs an adaptive sporting program. So, she can do skiing and things like that.

[00:35:38] FTKW: Oh, wow.

[00:35:39] Dale: A variety of mobility Issues. I see people doing like boxing and– and stuff with balance issues. So, they have a wide variety of different programs that they can specialize and cater, depending on what you want to do, what your goals are, and, they've, I think, I believe they've kept me walking this long.

[00:36:07] FTKW: Amazing. Amazing. So, I'm just going to ask you to repeat the name of that physiotherapy clinic again, if you don't mind?

[00:36:15] Dale: NeuroCore Pilates and Physiotherapy. They do have Pilates equipment there, that one is raised Pilates, I can't remember what the name of the equipment is, but they can use it for people who are in wheelchairs as well as for ambulatory.

[00:36:37] FTKW: Okay. That sounds like an amazing program. It's funny. I was just speaking with someone just recently, and I was stating-- telling her that if she can get her Pilates certification to be able to help people with various chronic complex medical conditions, it makes such an impact and change. Like even for the fibromyalgia, you know, there's women that are, or I should say instructors that are certified to help people with fibromyalgia with MS.

And it makes such a difference. Oh, wow. I'm so glad to hear that. So glad to hear that. Another question I have for you. When it comes to health challenges, and you were mentioning about your-- your husband and your children, I know when it initially happened, it must have been an extreme shock for your husband and for your children.

And if you don't mind me asking, were your children quite young at the time, or like in grade school?

[00:37:29] Dale: Adam was in grade five. Daniel was in kindergarten.

[00:37:33] FTKW: Oh, my goodness. Oh, my goodness. So how did it affect your husband in managing you with everything? And how did your children adapt and change to– or adapt to your situation?

[00:37:50] Dale: I mean, it was hard for my husband. It was, you know, a lot of worry trying to keep his business running. I had my aunties, my group of aunties kind of circled around and they provided so much support for us getting through that. You know, my-- two of my aunts used to pick the kids up from school, bring them home.

If I was in hospital, they'd You know, be looking after them and I couldn't have done it without them, really, it, you know, wider family circle to be able to care for all this, especially in the early years as the kids got older, you know, and they're more independent, it was, you know, easier for them to function.

[00:38:39] FTKW: Sorry?

[00:38:40] Dale: When I was sick it was easier for the family unit to function once they got a bit older.

[00:38:45] FTKW: Yes, yes. And with the benefits, funny enough, that because they, your children were so young, you said the other one, the youngest was in kindergarten, correct? Then they're able to grow and know you as this person.

It's not like it's such a huge shift and they're used to seeing you one way. For your eldest, maybe that may have been a hard shift for her. How-- how was that for her? I should just ask you, how was that for your eldest?

[00:39:11] Dale: Yeah, it affected them in different ways, for sure. The youngest was very anxious. He became extremely anxious in school and that was difficult, Madeline, the... it was more sadness, I think, right?

But they, they coped really well, considering, I think, because of those aunties being there, you know, they love, they love their aunts. And my mom also at that time still being there to help a lot. We did get everyone into counselling early on and I would recommend that if somebody's watching and they have kids, get them in and talking to somebody where they can talk, where they're not afraid of hurting your feelings, where the focus is on their feelings and without them feeling afraid to talk about what concerning what their fears are and (inaudible) not wait.

[00:40:21] FTKW: Right. You were saying to not wait, to have to go and see someone to be able to see a counsellor or a psychiatrist or psychologist.

[00:40:28] Dale: After diagnosis, if...

[00:40:30] FTKW: Mm-hmm.

[00:40:31] Dale: If you can access that and because getting the therapy is still covered by OHIP until those kids are 16. Anybody, I talk to so many parents who their kids get into later, like high school, and they can't find anybody, and that, then you start seeing bigger problems manifest on, and if you can get in and be proactive. (inaudible)

That those kids feel, (inaudible) you know, they can talk about what's happening and in an appropriate age-based way. They just played games with him and, and found, and found a way through and they both adjusted and they both turned out to be compassionate, lovely people.

[00:41:20] FTKW: Oh, that is wonderful. That is wonderful to hear. So, this– having the counselling sessions. I mean, it helped your children, it helped your husband, but I guess it helped you as well to transition.

[00:41:31] Dale: Yeah, I mean, my counselling didn't come until much later. Most of it in those years was focused on the kids. It's a lot harder as an adult. Through the Rumsey Center, if you go into their program, which is three days a week for, I think it was like 12 weeks.

Half the morning is spent on the physical therapy end of it. The other half of the day is spent on like occupational therapy, psychotherapy, pain reduction programs, and things like that. So, that's a good way, and it's a completely OHIP-funded program.

[00:42:15] FTKW: Oh, that's wonderful.

[00:42:17] Dale: And you can often repeat it.

So as long as Dr. Bruno, or whoever the physiatrist is, I think they have two there now, recommends you can go back into the program again. And sometimes they have little mini-programs. At one point I had to do speech therapy there. Again, amazing people, amazing program, very passionate.

[00:42:44] FTKW: So, just thinking what you were mentioning that.

In the beginning, you started off just focusing, which all of us have, you focus on addressing, getting the rehabilitation, getting the medications happening to be able to help to get you to a balance point. But as you're going through this, I'm just thinking your mental health-- that sudden shift from

feeling like you were a “normal person” and now it's almost like mourning the loss of who you once were. And sometimes you're thrown into it so you don't really have time to think about it, but at the same time, it takes a toll on your mental health. How did you manage that into the transition-- until you started getting counselling for that?

[00:43:23] Dale: Yeah, well, initially, the first year, it was like that shock. And then, I mean, losing a career too, right off the bat. Ever going to be able to return to this? What am I going to do? And with MS... unlike how– like, often when somebody has a car accident, they become quadriplegic or paraplegic. It's, they go from one state to another right away.

With MS, it can be a day-to-day, like you never know what to expect. So, you get to a point, and then you recover a little bit, and it's like hopeful. And then slam. And so, it's a constant process of going from, one state to another and having to adjust and redo things differently all over again. So, that causes anxiety and that's probably more than depression.

I think depression hit in the first year or two when I was losing that career and a sense of identity because as a teacher my identity was closely tied to teaching and the kids and-- and that was like an awful loss, and, and then it was the anxiety though, that comes through even more now, where I become hypervigilant of everything, even driving in a car.

I'm always waiting for his shoe to fall, from some disaster so even my poor husband, (chuckles) a passenger in the car, I'm like, what, what? Look out! Look out!

[00:45:10] FTKW: (laughing) You start breaking. (laughing)

[00:45:15] Dale: Always, you know, waiting for something to fall apart, right?

[00:45:20] FTKW: Yeah, yeah, yeah, it's, it's, it's not easy. And, so how many years until, well, first of all, for the anxiety, did they put you on any additional prescription? I know they tend to pile on the prescriptions, but I mean, in your case, sometimes you have to stop one to be able to keep the other going to, because some of them are contraindicative.

[00:45:43] Dale: It put me on Ativan...

[00:45:45] FTKW: Mm-hmm.

[00:45:45] Dale: ...on and off through the years. My concern with that, especially with my mom having Alzheimer's, is the link to Alzheimer's. So, I don't really like to take that one, but sometimes it's just necessary.

[00:46:01] FTKW: Mm hmm, mm hmm.

[00:46:02] Dale: You know, it's being in a constantly anxious state.

[00:46:07] FTKW: Yes.

[00:46:08] Dale: A good thing for physically or your heart or anything else.

[00:46:13] FTKW: Right, right, right, right. And so, and then at some point you said you started seeking counselling. Was this something that, the Rumsey program provided for you? Or is this something that you sought out externally?

[00:46:27] Dale: They offered CBD.

[00:46:29] FTKW: Yes.

[00:46:30] Dale: CBT.

[00:46:32] FTKW: Yes, CBT. I know what you meant. I was about to correct you. But yes, CBT.

Exactly. Cognitive Behavioral Therapy. Yes. And how did you find, because you did the mindfulness before you did the CBT, correct?

[00:46:43] Dale: I was doing it almost simultaneously.

[00:46:46] FTKW: Mm-hmm.

[00:46:47] Dale: I'd have a, you know, an hour of CBT and then we do mindfulness and then I go to speech therapy and then I go to occupational therapy. So you're moving around in the same building to these different things and having your lunch with the other—other, participants.

[00:47:03] FTKW: And how have you found-- are you on an ongoing maintenance program with the CBT or is it something where they just had the program and then you completed it and you just kind of do your own thing separately?

[00:47:15] Dale: I can probably, if I need to go again, it wouldn't be too difficult, but make an appointment and then she would recommend either, I have just the CBT or usually it comes as part of the whole program.

Yeah, it's usually part of like a package you sign on. Sometimes they have the mini, little mini kind of refreshers. Or they'll bring in for like, you know, two or three weeks to do a refresher on it.

[00:47:42] FTKW: Mm hmm. Mm hmm. Mm hmm.

[00:47:45] Dale: But generally, it's a longer, more intense program.

[00:47:49] FTKW: So, with your condition, I mean, you're living with it for many years now, how... your children were quite young when you were first diagnosed, but how have you approached parenting, you know, now with your condition?

How did, like, I mean... yeah, how did you, how have you approached parenting differently from before, beforehand?

[00:48:11] Dale: Well, in some ways, although I lost my career to be at home raising my kids. During years, I wouldn't have been because, you know, in teaching, I was putting in, you know, long days often, but I did have a chance to be home with them during those years.

And so, I just tried to find joy in that. And sometimes when I was just really ill, you know, the kids would just climb into bed with a book. Or we, I remember one, Christmas, just not physically in good shape and, just watching TV binging for a series binging for like two weeks, you know, we just try to, we try to find those, what you can do.

[00:49:02] FTKW: Yes. And find-- sorry, go ahead.

[00:49:04] Dale: When I was well, and there was a school trip, if I could do it, I'd do it. If I did it on my scooter, I'd have to sometimes, you know, finagle with school admin and say, I'd like to go on this field trip, but I can't go on the bus. I have to meet them there on my scooter. Can I do that?

And sometimes it'd be, "oh, we don't know how the procedure goes", blah blah blah. And sometimes you just have to push and be adamant and go, no, I need to be on this school trip, (inaudible) my son's health, you have to push and then I would just meet them there with whatever device I was having to walk with.

[00:49:45] FTKW: Good. Good. Good, good. So it's just really about finding the joy, you know, and They say making-- take lemons and make lemonade, but just really finding the joy in life in this new norm.

[00:49:58] Dale: Yeah, sometimes, you know, it's definitely different. And I went to Paris with my daughter when she was 18. There were things I couldn't do. Like I couldn't, you know, walk up to the top of Notre Dame or things that I couldn't do. But the little things, sometimes you just sit in the park and you notice the things that you wouldn't if you were in a hurry doing something else.

So and sitting on the park and you know, watching people or sitting in a cafe. You just see it on a different level sometimes and-- and you find joy where you-- you can.

[00:50:44] FTKW: Yes. Yes.

[00:50:46] Dale: And that's really important.

[00:50:48] FTKW: Okay. Okay. So, with Dr. Bruno or whom-- whichever other doctors that you're currently seeing, have you incorporated any integrated medicine, naturopathic holistic treatments?

[00:51:01] Dale: I have on several occasions. Not with Dr. Bruno, because she's pretty like straight science.

[00:51:07] FTKW: Mm-Hmm.

[00:51:07] Dale: I did see a naturopath for a while when I had, a bowel abscess that landed me in hospital for a long time, a really long time, because I caught C. Diff., from the end. I was in for four months with that one.

And I saw a naturopath when I came out to try to figure out how to, you know, build my system back in. And that was helpful for a while. In terms of diet, there's been so many conflicting things out there with MS that I think it just comes down to eating properly.

[00:51:50] FTKW: Mm-hmm

[00:51:51] Dale: Eating healthy food, it becomes so expensive, a lot of these diets. I know there was, which costs a fortune if you're having to eat only organic food and, grass fed, you know, meats and things like that.

It's, excruciatingly expensive on top of COVID and the grocery prices and delivery prices to have I need my groceries delivered. My husband also isn't well. He has his own issues. He has spinal stenosis, so his walking isn't good. So, when my daughter is able to, she, will do groceries for us. But I have them delivered, so that just puts grocery prices up, it makes it astronomical.

So, eating well is, is critical, but sometimes following these diets isn't realistic for those of us on fixed incomes. So, on my private insurance, I'm lucky to have any private insurance, it's very limited in the amount that you can access per year.

[00:53:02] FTKW: Right, right.

[00:53:04] Dale: $500 for a naturopath, which will cover, like, the sessions and the vitamins that you get when you leave, if you're lucky.

So...

[00:53:14] FTKW: Yeah.

[00:53:15] Dale: Yeah. So, I tend to stick with my doctor's advice, and I don't seek other than the physiotherapy, which has been central. I haven't gone for a lot of other therapies. I think I did acupuncture. That was brutal because if you're sensitive to trigger points and stuff, the last thing I want is somebody sticking something into my skin.

I'm so hypersensitive to touch that I just about went through the ceiling.

[00:53:52] FTKW: Yeah, yeah. It took me years, years, I think well over a decade. Or no, about 15 years before I could actually push to get through acupuncture. And they're like, Michelle, because of a specific situation, you really need to... and you just hear me screaming and you're like, oh my God, it sounds like someone's killing you, but it's that's how sensitive it is.

And I'm like, I'm sensitive, very sensitive because of the fibromyalgia. And then you got the two combined. Aye aye aye.

[00:54:21] Dale: I can't stand even massage therapy. I can't stand it. I can't stand anybody touching my legs. Especially. Or my arms, my upper arm, I can't stand. Physiotherapy, Ali has weight, because she'll cue certain muscles, like, to move them so that I can find where I am in space, because sometimes it's hard to tell, though.

You know, they want your arm to move a certain way, so she'll have to cue me and put her fingers and cue where a muscle is. And she's come to understand how much of that I can tolerate. But, even on a neuro exam, I can find that incredibly painful, which completely confuses most neurologists. That shouldn't hurt.

But that's, I'm telling you, it hurts.

[00:55:11] FTKW: It's gonna hurt because of the fibromyalgia.

[00:55:15] Dale: Yeah, I don't think neurologists are up on the fibromyalgia.

[00:55:19] FTKW: It's funny, every time I've had to get reassessed, whether it's a neurologist or a physiatrist, and the one thing they say is, we're trying to not cause a flare up.

And a lot of times afterwards, it causes a flare-up. And I, it took me- again, like years before I could actually go for a massage and they were like, you have, I said, I wouldn't, we would have to figure out where you could actually touch and it would still be screaming and I would have to like, very like scream and bear it and then we had to figure out, okay, what works.

It's still this excruciating, but just how the muscles, my muscles were acting up, it was needed, but for me, it's that light touch. Or even like I have my fan on because it's-- it's hot in here. But even that fan on the skin that burning feeling it's just that light thing. It's like, oh my gosh, it's-- it's excruciating. So, I am so sorry. (Chuckle)

[00:56:13] Dale: It can be worse than an actual pressure.

[00:56:19] FTKW: Yes. Exactly that light breeze or that light touch is worse than the actual pressure. Exactly. Exactly. Thank you for expressing that.

[00:56:28] Dale: Clothing textures.

It's, it's great. Like things like, jeans. I can't wear jeans anymore. Especially, in the winter because that cotton is cold, so cold, rougher textures, it just drive me crazy.

[00:56:46] FTKW: If you're going to, I love jeans, but it hurts, but my vanity kicks in. But in the wintertime, I, like even right now, I have on the big, the biggest pants just to be able to not have it touch my skin as much. But I wear something that's kind of very warm. And even though it's still painful to wear, but more soft just to separate the two textures, because it's painful, even a bra, it is excruciating, like...

[00:57:12] Dale: ever to find one.

[00:57:14] FTKW: Honestly, like I'll be, I'll be blunt as soon as I'm done with this interview, I'm taking it off because it hurts! Even your own underwear.

A belt. Even your socks, the shoes, it's

[00:57:30] Dale: Yeah. Yeah, it really does. I mean, I'm, I've never been a fashion maven from the beginning, so at least that part of my identity hasn't been too wounded by it. But I find just like leggings are the best for me that are just soft leggings baggy shirts, baggy t-shirts flannel sheets.

I can't, cold crisp cotton, I can't do on the bed. It has to be like flannel or something very, very soft.

[00:58:04] FTKW: Soft, yes, yeah. The thread counts, the softness of the sheets makes a difference. Even how the mattress is... how you lie on it because it's excruciating just even to lie down. I remember I was explaining to someone, I said, I just wish I could just float, float naked.

(both ladies laugh) And I would be happy.

[00:58:23] Dale: You remember the story, The Princess and the Pea?

[00:58:26] FTKW: Yes! Yes!

[00:58:28] Dale: That’s me!

[00:58:30] FTKW: I gave that example to someone years ago. I said, do you remember that story? I said, even on the mattress, that slight difference, I can feel it. I go, I feel like the princess and the pea. Thank you. I'm not the only one that feels this way. Yes, it's true. So true.

[00:58:44] Dale: And I have-- I have to have this gotta be eight pillows in my bed that every night my poor husband because he-- he lays very flat. And I am on a mountain of, you know, pillows, different pillows.

I, you know, I'm always on the search for the perfect pillow.

[00:59:03] FTKW: Oh yeah, oh yeah. This is a common thing that everyone says in the fibromyalgia community. We have all these pillows, the body pillow. Like even me last night, I had like about three or four different pillows and I still have my long body pillow because it just gives you that little ease. Yeah.

[00:59:18] Dale: My son he moved back from North Carolina for a while and he bought a Purple mattress down in the States. It's called Purple Mattress. And he brought it home and left it in his room. And every once in a while, like, oh, I'm just going to take over. He's, he's moved out again, but he left the mattress. I pinched it.

[00:59:41] FTKW: So, with the support that you have, you have your family support, you have your auntie's support and the different practitioners. Are there any social media groups that you go to help seek wisdom and continue to give you updated advice?

[00:59:57] Dale: There's a couple of, like on Twitter, a couple of like, a neurologist and there's a site called "MS News" that I follow. The problem with a lot of the MS groups online is that the security of information can be an issue. And, I did meet a lot of people with MS locally that were all still friends when we get together for lunch, although we don't go on the website anymore.

But, years ago, back in 2000, there was a site called the Massachusetts General Hospital, MGH, that had a really good group. But then it was kind of infiltrated with– we found that it was a study that the owner of this site was doing without our consent, where people, had multiple user identities.

And he thought that this was like an interesting thing to study. But sometimes one person would have 21 different identities on the site. And some of us started to figure out that there was something really weird going on. And so you, you just couldn't trust, kind of the integrity and, the honesty of letting yourself out there when there was another underlying purpose for getting this information and your reactions to it. Yeah, it was really weird for a while.

[01:01:32] FTKW: That's very sad to hear. I know with a lot of the Facebook pages that they provide a lot of support, some of them are private, and you have to go through a lot of the questions to be able to confirm that you are who you are, and you are there for the right reasons. And they, you know, the administrators try to look over to see what's going on so that if you are not even stating the right things or– or promoting things that you shouldn't be, then they will, you know, ban you or they will stop– close your whatever that post that you had, listed. But that's very scary because you want to feel confident to be able to share your experience and realize, oh, you know, this person seeing this doctor, this person seeing that doctor or this treatment and just to be able to share candidly.

But, that's, that's very disappointing.

[01:02:19] Dale: Yeah. And I mean, it's hard. Some people, we'll have a great experience with one doctor and they, you know, will bond with them and other disastrous experiences too. So, sometimes you have to, you know, weigh, that as well. That's because everybody's so individual with their MS experience, that, that.

it can get in the way, and sometimes you don't even know if somebody has a diagnosis, we often found that we get a lot of people who hadn't had diagnoses yet, that were searching for answers.

[01:02:58] FTKW: Okay.

[01:02:59] Dale: But, they'd be so anxious. And I mean, some of us on that group were very disabled. And so for a new person coming in, you could just see that this was not safe for them either.

It was not safe for them at that level to feel, especially my experience as somebody with 24 years. As opposed to someone coming in now who is 20 years old and has completely different medical medicine options and treatment options that are a lot more hopeful that...

[01:03:39] FTKW: Mmm

[01:03:40] Dale: during a group of us who are in our late fifties and sixties who aren't going to be able to access those treatments now and have a lot of damage is very devastating.

For those young people, and if there's a young person listening to this, I want them to understand that the, what they can access now to listen to the neurologist to try to understand the science behind the newer medications for MS. That they have better than any generation before of not being disabled, of not having the level of physical disa-- disability and cognitive disability that many of us in our 50s, 60s, and 70s have gone through. It's a lot more hopeful for them and to hang on to have a family that they'll be able to do that. And, I don't want them to have their dreams dashed by being in a group where people are very disabled and-- and ill.

It's not just, it's illness. You know disability I could have handled going back teaching in a wheelchair. That wasn't the issue It was the illness the constant illness the cognitive impact those, right.

[01:05:11] FTKW: Mm hmm. It's- it's funny. People don't realize how much the cognitive impact, the physical pain. I remember, I'm– I'm an Aquafit instructor and land therapist instructor for people with arthritis under the arthritis belt.

And one of the things that they teach us is that you could see a person who looks completely normal standing and you'd see someone who was bent over and the person who's bent over has no pain can still get around. You think, Oh my gosh, they're in the worst case. And the person who looks normal, is in severe pain and is debilitated because of that.

And... yeah, people don't seem to realize that that illness, that type of pain, the cognitive issues, the fatigue, and how debilitating that fatigue, pain, and cognitive issues can impact a person's body. It's, it's something, it's one of the reasons why I even decided to do this podcast, but it's, it's something that people have to be aware of.

It's not always what you can see. And it's true. If you could go back to work in your wheelchair. Not a problem... you know, at least you'd make that adjustment. It's still hard. Oh, it is hard.

[01:06:24] Dale: Yeah, but it's And I would have done it in a heartbeat but it wouldn't have been fair to my students, that the fatigue, you know, having to mark a paper, you know, it takes a lot of energy, and I was sick, I was in and out of hospital, so it wouldn't have been fair, I would have had supply teachers in endlessly, it wouldn't have been fair to my colleagues, it-- it wouldn't (inaudible) have been fair.

[01:06:55] FTKW: Yeah, no, I understand. I understand. One last question that I have for you. Are there any, MS, neuro-- neurological doctors that you'd recommend that, you know, off the top of your head?

[01:07:07] Dale: So, I've had sweat because my neurologist that I had for many, many years, Dr. O'Connor retired. And, you know, and there's a case where, I mean, he really (inaudible) is responsible for me still walking today because he was so heavily aggressive with treatments that were toxic, like, but we weighed that risk versus benefit.

I just said to him, I need to get these kids raised. Let's, like, do what we can. But another patient, a lot of other patients, couldn't stand him. So, you know, some people loved him and some couldn't stand him at all. He's retired, but there was a big shakeup at St. Mike's. They have a new, MS center there.

And so all of his patients, when he left very abruptly, they had to take thousands and disperse them across the system. So I haven't seen, my current neurologist is fine. But he didn't, hasn't seen me through the whole, you know, process and it's very secondary progressive. But honestly, they, (inaudible) for me, until, unless they come out with some drug and ram it through a study really quickly, you know, new drugs, 15, 20 years of development to get all the way through to the patients.

So there's not much neurologists can really do for me.

[01:08:37] FTKW: Mm-hmm

[01:08:38] Dale: (inaudible) I've been diagnosed, there's like wonderful neurologists, Dr. Ho I think,

[01:08:45] FTKW: Dr. Coe, you said?

[01:08:46] Dale: Dr. Ho with H.

[01:08:48] FTKW: Ho, okay.

[01:08:50] Dale: Ho, yeah.

[01:08:51] FTKW: And which hospital does she work out of?

[01:08:54] Dale: St. Mike's.

[01:08:55] FTKW: Oh, St. Mike's MS clinic. Okay.

[01:08:57] Dale: Yeah, I'd say they've got a number of really good neurologists down there and (inaudible) work out with someone that you're, you're not bonding with them, which like, you know, it takes a long time to see someone down there.

The waiting list is long, but switch if you're not comfortable. You have to have somebody who you can trust their opinion with that's going to be that respectful and listen to what you're saying. And if you don't have that relationship, switch earlier rather than later.

[01:09:39] FTKW: Yeah, yeah, that does make sense. That does make sense.

Dale, thank you so much for taking the time to share your life-- your lived experience with us here at Freedom to Know Wellness. It's been an eye opener, to hear your life and your experience, and it's been very informative and educational to myself, and I believe to all our listeners here.

Thank you again. And to our listeners, as I always close, reading information is one thing, but listening to a person's lived experience is another and paramount. And that's what we do here at Freedom to Know Wellness.

Thank you and be well.

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