

Multiple Sclerosis with Lisa Nice

Speaker Key:

VO Voiceover

CB Chantal Boyle

LN Lisa Nice

PS Paul Shriever

00:00:00

VO

Welcome to The Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

CB

Our guest is Lisa Nice, who has multiple sclerosis. Lisa works for the charity, Comic Relief, and is also part of their internal WE-CAN group. WE-CAN stands for Wellness, Enablement, Carers, disability, and Neurodiversity. So, Paul and I are very much looking forward to getting into that chat in a little moment, but welcome, Lisa.

LN

Thank you.

CB

Paul, let me just have a little chat with you to start off with. How are you doing?

PS

I'm doing all right, Chantal. It's been a while since I've done this.

CB

It has been.

PS

Yes, and so, I'm a little bit rusty, but I'm also excited, and it's nice to be back with you doing a podcast and a chat, and meeting Lisa, and having a conversation. So, yes, I'm looking forward to it.

00:01:19

CB

Well, The Sunflower Conversations now have been in existence for a couple of years, haven't they? Started off as a video interview format, and now we've progressed into podcasting. You started it, so, how do you see that it's evolved since then?

PS

It has changed greatly, and I think it was something that obviously, when it started off, was something that was literally at its beginnings. And so, it started off, to begin with, with more of a regular chat. It was also video-based, and it wasn't a podcast, so it was typically shorter. And I don't know whether we had quite as much purpose, or it wasn't quite as directional.

Now, things have changed. You're doing it now all the time, and I'm not doing it so much. And I think it has become more focused. We also do a bit of both, so we use that and repurpose it for both video and for audio, so that's something we can use for either. But what it allows us to by doing podcasts is to drill down and really learn about conditions, and then share those learnings with others.

00:02:43

So, that's, I think, what's really changed. I think, obviously, also, we've learned along the way about what works and what doesn't. For example, talking to somebody prior to actually having the meeting, I think, with hindsight, is something that is very, very useful. Just little things, making sure that people are comfortable. And still, I get nervous, and I am clearly now.

But it's about making people feel relaxed, and then speaking to us about their conditions, and obviously expressing and telling us what they are prepared to tell us, so that we can then share that information on our platforms to others who are similar. So, yes, I think it's changed, and it's got a lot better.

CB

I guess at the beginning, as well, it was informing people about what the Sunflower was, as well, in a sense, wasn't it? Its infancy. Whereas now, particularly in the UK, so many more people are aware of the Hidden Disabilities Sunflower. We've still got a long way to go, but as you said, it allows us now the space to actually find out more about people's health conditions, and really use this as a tool for learning, and expansion, and helping people on their disability-inclusive journey.

If they've got a loved one that's been diagnosed with something, and their mind is blown, it's a little insight into somebody's life who has that condition, and I think that hearing things from people with lived experience is just so important.

00:04:22

PS

I think you're 100% right, and I think now it has direction. And I think what we're trying to do is, we're trying to use that content that we get from people who we speak to, that are kind enough to talk to us about their conditions, and we then share that with society, with people. And that can be business based, as well as somebody in a family, for example, who needs to learn. And that's really important, so that hopefully we are spreading awareness and helping with those messages and understandings of other.

CB

Yes, and I'm excited to be co-hosting again. That's nice. I've enjoyed doing it on my own, because I like to chat, but it is nice to co-host so that our listeners get to know a bit more, just hear a little bit more from the team. And also, when you've got two of you doing it, you might pick up on something that the other person hasn't, so it just allows wider conversation. So, you're back, and we can expect to have you on here a little bit more often.

PS

Yes. Thanks for inviting me, again, and I'm looking forward to it.

CB

So, let's waste no more time, and let's welcome Lisa. It was ages ago that you and I had a chat about you appearing on the podcast, so thank you very much for giving up your time, and I'm really pleased that we've been able to make that happen. How are you doing?

LN

I'm good, thanks, really happy to be here. Thank you for inviting me along.

CB

So, can you explain what WE-CAN means? That's your wellbeing group at Comic Relief. What does it stand for?

LN

So, it stands for Wellness, Enablement, Carers, disAbility, and Neurodiversity. So, we cover quite a broad range of areas, and we wanted to come up with a name that was easy to remember, and really positive, because we think that whatever we're navigating, we can achieve it with the right support in place.

00:06:30

And it's just a really lovely group. It's full of amazing people. We all learn from one another. Part of our purpose is that we provide peer support to one another and create a safe space for each other. Everyone in the group has either direct or indirect lived experience of the areas we cover.

And part of what we do, also, is to build awareness and understanding across the organisation of these areas, and support the wider diversity, equity, inclusion, and belonging work at Comic Relief. So, for example, we might make recommendations, we might input into processes, we might review policies, etc.

CB

I love that. That's great. Two things I pick up on that is disAbility. It's written with a capital A, isn't it?

LN

Yes, that's right. So, we didn't want to remove the word disability, because quite rightly, people can be very proud to have a disability, but we also wanted to focus on the word, ability. So, that's why we changed that word.

CB

Yes, it's good. It's really good. And I also like the other thing that you say about it's a peer-to-peer support group, as well, so that people can have that chat with somebody who will give that understanding ear. Which is so important, because you can be going through so much with your health at home, and we spend so much time at work or working. To be able to have that opportunity to have a safe space, which is how you phrased it, is really important.

00:08:25

LN

Yes, and it's also having a common understanding of some challenges that you may face. Because I think when we're just advocating for ourselves, we tend to let things go a little more, but if we know someone else is experiencing it too, then we're more likely to take action. So, I think those kind of things really come out when you're having these conversations as a group and really listening to one another.

CB

That is so true. You do let things go for yourself, don't you? But if you hear somebody else is having a challenge, your warrior appears and you think, why can't I do that for myself?

LN

Yes, exactly. And then, I think if you become more aware of that, then actually you do start advocating more for yourself. But yes, I don't think it's a natural thing that happens for most people. Maybe some.

CB

Well, it sounds brilliant, and all credit to Comic Relief for getting that together.

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So, you have multiple sclerosis. It is genetic. Or is it genetic? And how does it affect you?

00:09:54

LN

So, no, it's not genetic that we know, but there are lots of unknowns. With multiple sclerosis, which I'll probably just say MS from now on, it's an autoimmune condition, so it impacts your brain and your spinal cord. And with the condition, your immune system mistakenly attacks myelin, and that's the protective coating around your nerves that enables those brain signals and messages to travel quickly along the nerve cells. So, when this happens to the nerves, it leaves lesions and disrupts the signals, so that causes various different symptoms depending on exactly where the lesions are in your brain and your spine.

PS

There's a few of them, isn't there, actually. I was looking earlier. Fatigue, optic neuritis, loss of vision, weakness of limbs, reduced coordination, balance problems. It goes on. So, yes, I'd imagine that's very challenging.

LN

Yes, it's very unique to the individual, because it varies based on where their lesions are. And yes, the list is really lengthy, because it can cause so many different symptoms. And yes, they don't fully understand why people get MS, yet. There's still loads of unknowns. They don't think that it's directly inherited from parent to child. However, family members may have a higher risk of getting MS. No one in my family has had it, to my knowledge.

CB

Does anybody in your family have any other autoimmune disorders that you know of? Because there are hundreds of autoimmune disorders.

00:11:49

LN

Not in my immediate family that springs to mind. Maybe if you go a bit further, but yes, there's nothing obvious. But yes, there's so many risk factors that apparently might increase your chance of getting MS, but again, it's a little... They can show the stats, show that it might increase your chance, but we don't know if that actually causes it. So, I had a vitamin D deficiency, so that could have potentially been one of my triggers. But we don't really know that for sure, either, because there are other triggers. Yes, it's all a bit unknown at the moment.

PS

Lisa, what interests me, as well... I'm sure Chantal will go on to asking you about this, but obviously these symptoms, I'm sure that would've been very challenging working out and being diagnosed. But it's like, well, when did it begin? Was it like, when you were very young, did you have symptoms of dizziness, for example, that were mild and then it became more acute? Or was it all together? And how on Earth do you then think, well, this is bad enough for me to actually go and seek advice, or getting it diagnosed?

LN

Yes, well, I would say there were definitely telltale signs that I would have no idea what they were. But with hindsight, which is a wonderful thing... But when it actually became a bit more, oh, there's definitely a problem now that I need to deal with, was I'd been in London all day. It was over Christmas, and I was staying at my parents'.

And I came back mid-afternoon, and I had really painful muscle ache. I had to lie down, because I just felt it all over. And I just suddenly felt so tired, and I just fell straight asleep. It was only afternoon, and I think I didn't wake up till the next day. And something just didn't feel right.

00:13:55

It continued on, so I went to the doctor, and then diagnosis started there. I had my blood tests, we realised my vitamin D was low at that point, so we thought, oh, that's it, we're going to fix it. But sadly, that did not fix it. It did actually get rid of the muscle pain at that time, but then slowly, other symptoms started developing.

CB

So, what are those symptoms? How are you affected by your MS?

LN

Well, it sort of depends. So, at that point, because I have what is known as relapsing-remitting MS... So, there are three different types of MS. There's primary progressive, secondary progressive, and there's relapsing-remitting, and I have the latter. And that means that I have a relapse, where my symptoms come on really strong, and then they go into remission a little. Some things hang around, stick around for either forever or for a while afterwards.

But obviously, when you're going through diagnosis, you don't know any of this. So, when I had my first relapses, I didn't know what it was, and I had loads of symptoms that came on gradually. I started to struggle walking. I would trip over and fall flat on my face. I developed a foot drop, so I was constantly worried about tripping. My walking...

CB

Can you explain that? What is a foot drop?

00:15:26

LN

A foot drop. So, that's where your foot drags on the floor, I think, is how I would describe it. So, you don't release, but it's not pressing properly on the floor. So, yes, you're just more likely to trip up, and it makes it difficult walking. And yes, what else happens? My walking's slowed right down, as well, I think because the brain signals weren't communicating properly. I just couldn't get my legs to move faster. It was very frustrating.

PS

Lisa, was it scary? Did it really alarm you when those symptoms first appeared, or did they just become progressively worse? Is it something that just suddenly happened and you're like, what is happening?

LN

It was so slow. And for me, in my experience, first of all, I put it down to vitamin D. So, I was like, that's okay, we found a solution. And that was just... Not just muscle pain, it was quite horrific, but at that point I was like, that's fine, this is going to end. And then, after that, I got in my head, which I think has happened to other people, too, that it was a trapped nerve. So, I was thinking, that's fine, too. It will be resolved.

CB

Fixable.

LN

It didn't really explain everything, but I think you cling on to some kind of explanation that works for you at the time. And to be honest, even though I know people with MS, it didn't even occur to me that that was what it could be. I think I got more scared when it progressed to my hand and I lost the fine motor skills in my right hand, so we think I must have had another relapse. And I couldn't grip, so I'd be holding something, I'd think I was still holding it, but it was smashed on the floor.

00:17:28

CB

Oh my gosh.

LN And I couldn't handwrite anymore, and that for me was... I don't know why, but for some reason, out of everything, that was the thing that really upset me the most and I felt most emotional about.

CB

And it sounds like it would come and go, so you could hold something one minute, and then all of a sudden, it's gone.

LN

No, not at that point. Yes, that was pretty constant, to be absolutely honest. Maybe I could hold it for a couple of minutes. Not even minutes, seconds. But yes, to be honest, at that point, I just got to the point where people had to cut my food for me. I couldn't open jars. All those kind of real practical difficulties, like doing up the buttons on my clothing was really difficult, because my coordination also wasn't really there.

So, yes, those kind of symptoms were really tough, and I feel quite lucky that once I did get diagnosed, it did turn out to be relapsing-remitting. Because for some people, once they get those symptoms, that's it. So, that's really, really hard. And it's not doing away from my experience, because it's also hard when it's relapsing-remitting, but I feel lucky to have that remission period.

CB

Yes, you do get a bit of a reprieve from it. But again, that just speaks to your approach, your mental health approach, because some people with relapsing-remitting wouldn't feel fortunate. So, that says a lot about you. And the muscle pain interests me, as well. Does it feel like, you know when you're getting flu and you can't move your limbs, is it similar to that? Or can you describe it?

00:19:34

LN

Yes, it has been. But I also had, I think it's got a medical name, but I don't actually know what it is. Sorry. But I actually had it where I couldn't even rest my own finger on my leg without the muscle feeling in agony. It literally felt like I had whacked myself. So, yes, I think it's actually got a name, but I'm not sure what that is. I'll have to look that up. But yes, it's just that level of sensitivity, it just felt so painful. And obviously, this is all invisible symptoms.

And another one, one of the more random symptoms, is called the MS hug, and that was just such a bizarre symptom when I was experiencing it, because I felt like I was wearing an elasticated skirt inside my body that was too tight, way too tight, and all the time it was hard to breathe. Which sounded, even to me, like what is happening? This is so weird.

But actually, when I got diagnosed and looked into different symptoms, it's actually a symptom called the MS hug. And again, that probably feels slightly different for different people, but I definitely recognised what I was reading as what I had experienced. And then, random symptoms like my toes felt like they were stuck together.

CB

Oh, gosh.

LN

I had a couple of weeks where I just smelled unclean, and that I really found hard, too.

00:21:13

CB

Yes, and I'm sure everybody around you was saying you don't smell at all.

LN

Yes, it would literally be like I could've stepped out the shower, and to me, I smelled unclean. So, I knew it wasn't true, but it still smelled that way to me.

CB

I think that's anosmia, I think that's called, isn't it? When the smell is gone away, it's tainted, it switches. My goodness. That's a lot. So, did you have to make changes to your life?

LN

Yes. So, I've had to slow down. I don't have all of those symptoms on an ongoing basis. I think my daily symptoms now are more around fatigue, brain fog. I do still sometimes get muscle pain. Yes, those kind of symptoms more now. So, I have to plan my time in a way that I wouldn't have before. I've always been really social, I always had lots in the calendar, but I've had to really cut back. And I always refer to the spoons analogy. Do you know that one?

CB

I do know it, but please say again, because I think that our listeners who haven't heard it will be keen to find out what it means.

LN

Yes, so, the analogy is that you have a certain number of spoons each week, and they represent your energy. So, each week, you have to ration them across the week. So, you have to be careful not to use too many spoons on one day. So, for me, I don't want to use up all my spoons, because then the remaining days of the week are going to be much, much tougher. So, yes, I do have to plan a lot more.

00:23:04

And another change I find is that I have to use public transport or taxis more, because if I walk too much or exert myself, then my body gets really physically tired, and then I can feel some symptoms coming back or getting worse. And although I do need to plan, I also have to be more open to adjusting plans, both inside and outside the home. So, if my concentration span is being unkind, then I can't sit and watch a film. If I'm feeling fatigued, I can't go and make a journey. So, I guess everything's dictated a lot more by my body.

CB

And it sounds to me like you really listen to your body.

LN

I've had to, I think. I think I didn't for a long time, but yes, now I don't really have a choice. And yes, you just come to realise, I think, that if you don't listen to your body, then you're going to do yourself a disservice. You're going to have to make up for it. So, it's really thinking about the bigger picture all the time and managing that.

PS

I think also, you don't know what you're going to get, almost, from week to week, right? So, it literally has to ebb and flow. So, it's not like there's a consistency here. We're talking about one week you could feel actually quite good, and then other weeks you could feel terrible. So, it's about how you react. Do you have learnings from that? Is that something you've become better at with time?

LN

Yes, I think so. I think I'm beginning to. Maybe it's still an ongoing thing.

00:24:52

PS

For example, if you're having a bad week, do you know how to deal with that slightly better than perhaps you did two or three years ago, for example, or when you were first diagnosed? I'm just trying to gauge your coping mechanisms, how you deal with things. And have you got any tips for people listening on what to do, how to treat something if something's coming and you're feeling it? Is it something you pre-empt, you see it, you feel it coming?

I get migraines, and I know when they're coming. So, I can feel it coming on, and so I go somewhere, and I know how to deal with that with experience. I'm just curious to know how you deal with that.

LN

Yes, I think a lot of it is acceptance for me. Fatigue can just come on so suddenly, and that's probably the biggest issue. And you can try and manage it when exercise, with diet. There are various things that definitely help. But ultimately, you are likely to still get fatigued from time to time, sadly.

And for me, I think I would just say accept it. Have a rest. Accept that you can't do XYZ at that time, and make sure you just look after your body. Because then you're going to come back, hopefully, more productive. And I guess I would make an adjustment. Like maybe if I was going to go into work that day, I wouldn't. I would work from home. If I had two social occasions, maybe I might feel up to attending one. Maybe I might have to drop the other.

00:26:28

CB

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You work full time, Lisa?

LN

Yes, that's right.

CB

So, do you have a combination of working from home and working in the office to accommodate for this low spoons?

LN

Yes, well, to be honest, we've got a flexible working policy anyway, so that's across the board, so we've really lucky. And yes, I balance it out. I try and do it based on my work priorities, but if it did come up that I didn't feel well enough that day to go in, then it would be fine. I would just swap my days around.

CB

And I think, as you said, you've got to put your health first, because otherwise you are going from being on your back and on your knees, and then you're not going to be any good to anybody, including yourself. So, you have to put your health first, don't you? And then, how do you emotionally feel when you've been invited to two events, and you know that you just don't have the fuel to do both of them? How does that make you feel when you've got to decline events?

LN

Yes, it's tough. I think that has been one of the hard things, actually, because my natural instinct is to everything, or try and do everything. And I do find it quite emotional. Or if I have to weigh up, if I go to that dinner, I'm either going to have to pay lots of money to get there and back, or I'm going to have to do a really long walk, which means my symptoms are going to come on. So, even things that seem like they shouldn't be a big deal because they're just hanging out with friends round their house or something, for me now, it's much more complicated than that.

00:28:17

Yes, I struggle a lot with that, to be honest. But there were a lot of changes that happened in the world since my diagnosis, and in some ways, I guess it's sort of eased me in, because everybody had to change, and everybody had to go out less. So, I think it's actually only now becoming harder.

PS

Lisa, can I ask a question, also, about your family and people that are around you, in terms of how has it impacted them? So, if you've got loved ones or people that are around you, obviously they're going to need to change, as well. And it's also how it impacts loved ones around you, and that interests me. You obviously need help now. You need support, perhaps, in certain ways that you perhaps didn't have before. Has that changed greatly?

LN

Not on a day-to-day basis, I would say, with my loved ones. But definitely during when I have my relapses, for sure, 100%. My family were back and forth, they were absolutely incredible, checking in on me. As I said, I live alone, so if I couldn't open a jar, then that's a real issue. But I've got amazing friends who live nearby, and they've also just been incredible.

And ones that live further afield, I stayed with some friends. People have cut my food for me, they've been there for me, they've put up with me just sleeping all day and being tired by going for a shower, and then having to go back to bed. All those things. And I feel so lucky.

00:30:05

And my advice to anyone is that, if you do have support offered to you, then honestly, just take it. It's so hard. You want to say no. You want to keep doing everything yourself. But the reality is, you can't, and actually the only way you're going to get out of that situation is to do your best to rest and recover.

PS

Lisa, have you had any kind of long-term diagnosis with this? How do you see this progressing through your life, your condition?

LN

For me, I try not to think about it too much, to be honest. I always try and focus on the moment, because that's what I know and that's what I can deal with, and I think that's true of everyone in life. So, I think you can really scare yourself if you start thinking too far ahead to where things may go. I think you have to be mindful of them, and you have to look after your health in the best way that you can, like eat well, exercise, do all the things that are recommended. But for me, it's all about being in the moment, and one step at a time, quite literally at some points.

PS

I think that's a very healthy way of looking at life, actually. So, I take my hat off to you for that. I think that's great. I think a lot more people could do with a bit of that. So, yes, that's really good.

Just coincidentally, just jumping completely out of this conversation, both my parents worked for the Multiple Sclerosis Society years ago. And my parents used to take us all

around. We used to visit lots of people that were very much dependent on help and support. So, it's something actually I feel a little bit like I'm connected to, in a funny sort of way, because they had a static home by the coast, and it was for anybody who had MS. And we used to go up there all the time. My dad used to check it and make sure that it was running properly, and all the rest of it.

00:32:04

CB

Lovely.

PS

Yes, we used to have a lot of people round that had MS, and certain people, I remember mums were literally dependent on their children looking after them, for example. So, I know that there are some very severe cases, and also some not so severe cases. Is there medicine and treatments, Lisa?

LN

Yes. There are so many different treatments. I couldn't possibly even know them all. But basically, some people manage from diet, if, I guess, their symptoms aren't severe, or for other reasons they may choose to go that route. Then, there are a range of disease-modifying treatments. So, you can't cure MS, but you can try and manage it.

And yes, it's quite overwhelming when you first get diagnosed, because you have to make a choice, and obviously you want to make it as soon as possible, yet there are so... It's like with anything when you pick a medication, all the risks are presented to you, and you're already coming to terms with what's happening with you, and you're also trying to rest and recover. So, there's so much going on at that point in time.

But there are great resources available from both the MS Society and the MS Trust. They're amazing. And I was eligible for a treatment called Ocrevus, because my MS was considered highly active, because I had two relapses within that first year. So, first was the one that caused me to have the issues with walking, and then the one that caused me to have the issues with the hand.

00:33:51

So, I was quite... I always call it a weird kind of luck, because that medication has worked so well for me. So, although it was quite a bad time, it meant that I was eligible for this treatment, which I think I'm very lucky to be on.

CB

Yes, I see what you're saying.

LN

Yes. So, I have six-monthly infusions, and it's just worked really well for me. Touch wood, there's been no visible progress in my MRIs since I've been on it.

CB

That's good.

LN

So, that's really amazing.

CB

That is good news.

PS

And Lisa, can I just quickly ask, then? So, you talk about treatment. I'm curious to know, and obviously you don't have to disclose this, or do you have medication? Do you have daily medication? Is there lots of medication? Do you get fed by the NHS now weekly pills that you have to take, and so on and so forth? Is that something as well as the treatment?

00:34:55

LN

Not for me. I can't obviously speak for anyone else's unique situation. But no, not for me. I do think it's pretty standard that people with MS have to take high levels of vitamin D, or we're recommended to, so I do take vitamin D every day. But that's it, really, because the six-monthly infusions manage my day-to-day.

PS

Good.

CB

How long did you say, sorry, when you have the infusion, is that half a day at the hospital, or how does that work?

LN

Yes, pretty much. Yes, go in the morning, normally out early afternoon.

CB

And do you feel instantly like, oh, that's given me a bit of a boost?

LN

No, the opposite. It's more like it makes me tired, because I think the way that it works is that... This could be slightly wrong, so do not quote me on this. But I think it aims at the CD20 markers and attacks those in your blood, because they think that's what your immune system is trying to attack mistakenly. So, therefore, I feel quite tired after my meds, and that normally lasts for me for about a month afterwards.

CB

Oh, okay, so it's pretty intense.

00:36:19

LN

But for some people, they then go back to work straightaway. So, for me, it doesn't really work, so I tend to take a few days' rest, and then I would just try and take it easy for that first month. But also, it can vary from one lot of meds to the next. There's no set rule. I guess maybe there's external factors that make a difference, too, and other things that are going on. I find winter harder, for some reason, but other people find summer harder.

CB

Oh, right, okay. Because when we spoke to somebody who has lupus, and traditionally for people who have lupus, the sun is actually not helpful at all. But it's interesting here, where you could say for some it is, and some it isn't.

LN

Yes, it can be completely different person to person.

CB

We touched on this earlier, about being at Comic Relief and working full time. Are there any other adjustments you have? You've got the flexible working, but everybody has that, but if you didn't have it, it's something you would definitely request.

LN

Yes, for sure. And it was also recommended to me, when I had an occupational health assessment, to work from home one or two days a week. So, yes, I do. I have made an adjustment in more recent months where I compress my hours. So, I try and take off Wednesday mornings to rest, because I just find that means that by the weekend I'm not quite as exhausted. Because sometimes, on a weekend, I might need one rest day, for example.

So, Comic Relief also gives me leave for my medication days, and any appointments I need to go to, they're very relaxed about it. But aside from that, there's nothing specifically. But most importantly, my boss is just so supportive. He trusts me, which is really important. And so, provided it doesn't interfere with any specific work commitments, I can flex around.

00:38:25

So, if I'm feeling fatigued, I can have a nap and come back to work later, and just work a bit later into the day. Or, as we said before, if it's an office day, maybe I wouldn't necessarily go in. Or, for example, I might avoid rush hour. So, all those kind of adjustments, however small they may sound, can make such a huge difference. And yes, I'm so super grateful to Comic Relief for always supporting me. Since day dot, since my day of diagnosis, I've felt very supported.

PS

When you were diagnosed, were you told about how to then move forward and treat it? Were you sat down? Was there any kind of literature or anything given to you that said, right, you have this condition, and you now need to be mindful of this? Or was it something you've had to piece together and learn? Because you strike me as someone that's also taken it upon yourself to explore and work out and learn yourself, and I think you need to do that.

And we also pick up a lot of that, I think Chantal will agree, where people tend to not self-diagnose, but they learn about their conditions a lot themselves and work it out. Rather than have somebody say to them, right, you've been diagnosed with this, and actually, these are all of the points that you may have to be considering moving forwards, this is going to impact you in your daily life.

00:39:50

LN

Yes, it's actually quite hard to have... You do. You have an MS consultant, which is amazing, but that's after diagnosis. And I think one of the hardest things was during diagnosis, it's almost like you just need someone to say to you, we think it might be this, and that means that you should probably just rest for a while.

I think that permission to rest piece is really important, because I didn't give it to myself. And other people might've been saying it to me, but I wasn't going to listen to them, because I hadn't been told it. So, I was like, no, I'm just pushing on. There might not even be anything wrong with me. They just think this might be it. Even though it was obvious there was something wrong with me, your mind does go everywhere, right?

PS

100% agree with that. I'm like that. It's like, oh, that's something else. I'm being over the top. Or I don't know, whatever. You're kind of self-diagnosing, aren't you, and saying that's because of this, and it might not be that. But actually, there's something seriously going on.

CB

Somebody was telling me that our brains are almost programmed to fight against us. I don't know where I heard that, but what you two are saying with your lived experience, it sounds definitely true.

LN

Yes, exactly. So, I feel like with MS, I'm really lucky, because although it's really sad, there's a massive support network out there, because so many people do have the condition.

00:41:24

CB

It's 190 people per 100,000 in the UK that have MS is the stat I saw. I don't know if that's something you're familiar with.

LN

I know it's a lot. I don't know the exact stats. It's just incredible, isn't it? So, I think one of the things that really made me think when I was going through diagnosis, because you have so many rule-out tests, that I literally was looking up every single thing. I was doing all the things you're not meant to do, and I wouldn't advise anyone else to do. I was looking up everything it could be, seeing the different support out there, all that kind of thing.

And I did feel very, very lucky, in that weird, bittersweet way, that there is a big support network out there. There's lots of information. I went to some focus groups for the newly diagnosed. I went to some information days. I happen to have two friends that actually have MS, so I met with them, and that's invaluable. Absolutely invaluable, just being able to have those just really relaxed conversations, and say something to someone, and they feel it, they know it. They're just like, yes, that's it.

PS

So true.

CB

Chatting with other people having a similar experience has been a very important part of the process for you.

00:42:51

LN

Yes, definitely. And then, I did join some Facebook groups. There's a lot of support out there, too. They're run by people with MS, so that's really super kind of them to do that, because it takes a lot of work. And I've dipped in and out of those, because it was particularly helpful going through diagnosis, but I will say I kind of have to step in and out of support, too, because it can become so intense.

CB

You're right, yes.

LN

Yes, exactly, so it's just that knowing when I need that support, and to step into it, and knowing also when actually I can just get on with things at the moment.

CB

Yes, and not feel guilty about that. That's okay.

LN

Yes, exactly.

PS

Why are there three times as many women as men with MS? That's interesting, isn't it?

LN

I don't know if that's really known. They may have some idea around it, but I don't have any answer to that. There's also some links to climate. I think this is right, that you're more likely to have it if you're in colder climates. But yes, there's also a link with anxiety, but that's a bit chicken and egg, as in which came first?

CB

That's so interesting what you say about the colder climates. It's autoimmune, but it's kind of neurological as well, isn't it?

LN

Yes. It's also neurological.

CB

I was listening to something recently about, you know how everyone's getting into ice baths, and Wim Hof has really led the way on it. And now, if you look at Instagram, every celebrity's got an ice bath in their garden, and they're visiting themselves getting into it.

00:44:43

But there are supposed to be some major health benefits, but our brain tells us traditionally, or I guess when it's fighting against us, that cold is the enemy. And so, we are not embracing that and actually using it to free ourselves and release ourselves. And actually, once you start doing that, which is why it's been so revolutionary, although it's not anything, cold is cold...

PS

Yes, it's horrible.

CB

Yes, like people go and they climb up mountains in just their shorts with Wim Hof, and then jump into a frozen lake at the end, and they feel exhilarated, and they feel amazing. So, that's quite interesting about that. I wonder what research has been done. But anyway, we can't talk to you all day, although we would like to.

PS

But yes, it's not going to happen.

CB

What do you think about the Hidden Disabilities Sunflower?

LN

Oh, I think it's amazing. So, I had seen it around, I'd seen people wearing them, but I didn't know too much about it. But our wonderful head of EDI came on board, and she brought it to my attention, and I hadn't really thought of it as a workplace tool. I knew that it was helpful in if you were at the airport, so I saw it more in those kind of situations.

So, we had some discussion around it, we did some more research, and then we just saw what a brilliant thing it is, and we decided to recommend that Comic Relief implemented the scheme. So, yes, we're really, really happy that we did that.

00:46:31

CB

And how's it gone? Have you had any feedback from colleagues?

LN

Yes, it's just been so positive. So, we tied in the launch of the scheme with the launch of our WE-CAN employee network group. And we also shared the launch of our partnership with Business Disability forum, as you know, because you were there. Thank you very much. And we received such brilliant feedback from colleagues. Honestly, it was just overwhelmingly positive.

And we actually ran out of lanyards after the launch, and had to order more, and I'd actually been concerned people wouldn't actually take them and wear them. So, that just felt like such a great thing that people felt comfortable. And the launch prompted some really open conversations, people saying what a big step forward it was, how they now felt that actually they wanted to talk about their conditions or their situations, and they hadn't really before, ever, in a workplace. So, that was also absolutely brilliant.

And others just said how grateful they were to understand more about it in general. Like if they're out in public and they see someone wearing a Sunflower lanyard, they now know what it means, and they can help them, or they can give them the understanding they need,

or the space. So, yes, just all in all, it's created so much positivity, and I'm so happy that we have launched that scheme.

00:48:05

CB

We're delighted to hear that.

PS

Love that. Love that, Lisa. Very well spoken.

CB

Yes, thank you. So, we normally end on a question of your advice, but you have peppered a lot of advice throughout the conversation. So, I don't know if you have anything further, or if you wanted to reiterate any of the advice that you've given, or the charities that you approach. But the question is, do you have any advice for someone who has recently had their diagnosis and feels like the rug has been pulled from under them?

LN

Yes, it's really the same as before, that I said that I give myself the same advice. So, stay in the moment, slow down, take one step at a time, because it is totally overwhelming. You do have decisions to make, and lots of them, and some of it's quite complex. So, I think just one step at a time, be kind to yourself, rest. Rest is my big one. Give yourself that permission. And yes, try not to go racing ahead to what might happen, because it might not. So, you just need to deal with what is happening in the moment.

And yes, embrace all the resources and the support groups that are available to you, and the offers from friends, family, colleagues, because people are really, really kind, and they do genuinely want to help. And it makes such a massive difference, and I feel even emotional thinking about how much people have helped me.

00:49:41

CB

Yes, you've got some very special people there in your life, Lisa.

LN

Yes, for sure.

CB

So, it's good for gratitude, and to be aware of the things that we should be grateful for is important. And if it brings a tear to your eye, then so be it.

LN

Absolutely.

CB

Paul, I just wondered, if you just wanted to finish off with the statistics. You had a little Google whilst we've been chatting. I just wondered if you wanted to talk through the statistics that you found. The one I found was 190 people per 100,000. So, I don't know whether your one is the same thing. [Overtalking].

PS

I think there is slightly more, so I'll just quickly read it out. It's estimated that there are more than 130,000 people in the UK diagnosed with MS. That's 1 in 500, with about 130 people being diagnosed every week on average. Which is...

CB

A lot.

LN

Huge.

PS

It's a lot. It's commonly diagnosed in people between the ages of 20 and 30, which is also quite young, and there are roughly three times as many women with MS as there are men. And Lisa, it's been lovely to talk to you and meet you, and thanks for sharing. And you've been brilliant, and very articulate, and it's been really enjoyable.

00:51:08

CB

We will put the details of a couple of charities, if you send me the links, we'll put those in the show notes so that people can access the support that you've been talking about. So, thank you very much for your time, Lisa.

LN

Thank you. Thanks so much for having me.

CB

If you have enjoyed this podcast, please subscribe, like, and share to help raise awareness of non-visible disabilities and the Hidden Disabilities Sunflower. If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner.

VO

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