

## Parkinson's with Eve Jensch

**Speaker Key:**

CB Chantal Boyle

SC-R Scott Casson-Rennie

EJ Eve Jensch

VO Voiceover

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

Welcome to The Sunflower Conversations. I am your host, Chantal, and I am joined today by my colleague Scott. Scott works for Hidden Disabilities Sunflower in Ireland, and this is a real treat to have him with me and sharing this chat that we're going to have. How are you doing, Scott?

SC-R

Yes, not bad. Not bad, thank you. And thank you for having me today. It's very rare I get let onto the public things for the Sunflower, so it's quite a treat.

CB

Good behaviour. We're allowing you in. And our guest is Eve Jensch. Eve is 37 and was diagnosed with Parkinson's two years ago. That seems to be quite young, so Eve's going to talk us through what her experience has been so far. But first of all, Scott, I just want to ask you, as you said, you haven't really had the opportunity to do very many Sunflower Conversation podcasts yet, but you are a podcaster extraordinaire anyway.

00:01:29

SC-R

Yes, I do have a few podcasts myself, and I've also guested as well. So when Eve, before we started recording, you said that she was a bit nervous, and I totally understand that.

But I love doing podcasts because the conversations can just go anywhere, and it's fascinating listening to other people's stories because that's what it's about, isn't it? We need to hear other people's stories to understand the lives that they are living with the conditions that they've got. And that's why The Sunflower Conversations is a really great part for the Sunflower globally, not just in the UK or Ireland.

CB

That's right. And so, hopefully, if anybody's listening, whether you're in Ireland, Scott's based in Ireland as I mentioned, and Eve is also based in Ireland, do get in touch. But it doesn't matter where you are in the globe. We'd like to hear from you and we'd be very happy to hear your story because I think that's how we can help grow the knowledge of the Sunflower, but also just increase understanding and awareness of non-visible disabilities, full stop.

00:02:28

So, let's not waste any more time and let's jump into it. Welcome, Eve. Thanks so much. As I mentioned, you live in Ireland, and Eve has got three children and her husband.

EJ

Yes.

CB

So she's a busy lady. So thanks for taking time out to join us to talk about your lived experience of Parkinson's. Parkinson's is a progressive neurological condition, and this means that it causes problems in the brain as the cells stop working properly, and over time stop producing dopamine.

So, I know you've done a lot of research and investigation yourself, so I want to hear, Scott and I want to hear from you what Parkinson's is and how it actually affects you.

EJ

Parkinson's can affect different people in different ways. So, if you know one person with Parkinson's, you literally know one person with Parkinson's. There's a whole variety of symptoms that come with it. So, for myself, my primary symptoms are tremors and rigidity. What you don't see right now is that I'm sitting on my hand to stop the whole setup here from shaking, and that's probably something that I would do quite often, just to get a little bit of calm into my body.

00:03:48

And then there's a whole range of secondary symptoms as well. They're not

always permanent, so they can pop up as they like, and when they're least expected usually. So, for me that tends to be digestive issues, muscle cramps, which is also called dystonia. Basically, for me it's the right side that's affected, so my right leg, my right foot, my right arm will tense up and just do, we call it the Lego hand.

CB

Okay. Explain the Lego hand.

EJ

Well, you know the little Lego figures. They have that kind of hand. So, when I have dystonia, it just cramps up into this kind of claw.

CB

That's right, yes, because they're ready to hold a cup or something like that, aren't they?

EJ

Exactly. So we call it the Lego hand, but unfortunately, I wouldn't be able to hold a cup with it. Well, I can hold a cup. I would spill the contents. So, that's the dystonia. You have mental health issues, insomnia, apathy. That's just for me the most common ones, but there can be an awful lot else in the background.

Generally, that would affect me in a way that certain things like preparing a meal, for example, takes longer than usual because the motor skills will decline over time or even over the course of the day, depending on how your medication works. Tremors will make everything an awful lot more difficult, so eating, carrying a glass of water, like I said, anything that involves precision will be affected there. The dystonia hurts. There's constant tightness in my arm, my hand, my neck, my leg. So, that's the side-effects of that.

00:05:39

The insomnia isn't currently affecting me that much. It has last year an awful lot, where I would have sat up until about three, four o'clock in the morning, and then you have to be up again at six o'clock in the morning with the kids. But right now, it's fine, but the dystonia has me up a little bit in the evenings until I'm really tired to go to sleep, because I wouldn't really be comfortable lying down or sitting. I'm much more comfortable standing or walking.

So there's very little rest and I'm always tired. So, yes, that's my Parkinson's at the moment.

CB

So, you mentioned the right side of your body for all of the symptoms. Is that

because it's neurological then?

EJ

It tends to start on one side of the body. So it's not always the right side, but it's quite typical that it starts on one side of the body, either the left or the right. There's no real preference or a typical dominance of that. And then over time, it will spread to both sides of the body.

CB

I see. And you just explained so much within that first opening thing. I really needed to try and catch on to all of it. But the tremors, just doing your basic things around the house, as you said, preparing dinner.

EJ

Yes. Anything. Anything really.

00:07:02

CB

So you're potentially in a precarious situation all of the time then really. Hot water, sharp implements.

EJ

Yes. It's anything really. I'm trying to see the humorous side of it. I do a lot of social media and I have a series, if you want to call it that, things I can do with Parkinson's disease, and where I do the things that I can do with my right hand and just show it and make it funny a little bit. So also show my kids because they sometimes enjoy it. It's a bit of, let's sit on Mama's leg while it shakes, and it's a whole source of entertainment for them.

CB

Bless. That's good. It's making them not scared of it.

EJ

Oh, absolutely. I think they're young enough. I have seven-year-old twins and a four-year-old, so I think they're young enough to grow up with it and not be learning about as they're older. It's just a fact of life.

CB

When did your symptoms first start, and what were they? I'm assuming this has been a gradual increase in symptoms, that the first lot that you said wasn't all on day one?

EJ

Yes. No, my first symptoms that I can remember started in early 2020. And actually, I think I've done a video on that recently where I spoke about it. I very vividly remember the first time I've noticed my first tremor. I was sitting on the floor playing with my kids. I think they were about three at the time. We were playing cards, and my foot was just pulsing a little bit, not visibly, just on the inside. I was like, oh, that's a bit odd, but surely that'll disappear. Famous first words.

00:08:44

And it kind of just went from there. I think about a year later it was my whole leg that was shaking, and my arm had started at that time. And that's when I started going to see doctors about it. And it took about another year to first of all find someone who's interested in actually dealing with it and not just putting it up as psychological.

CB

Oh dear.

EJ

Yes. I've had referrals to psychiatry and everything. And then the diagnosis itself was fairly quick, once I had found someone who actually saw that something was going on.

CB

Is that why you said about it affects your mental health? Does it affect your mental health because of how you are looked after and responded to by people?

EJ

It absolutely can. It's definitely part of it, because for about a year I sat listening to two doctors telling me that, oh, it's all in your head, which to be honest it ultimately is, but they putting it up, because I've had a longstanding history of anxiety and depression anyway. So they're putting it off as, well, this is just you and there's something going on with your mental health that's translating into your body.

And then I actually went to see a psychiatrist who has a background in neurology, and she said, no, this is not psychological, you have to go see an actual neurologist who will listen to you. And she recommended someone, and he did the rest then.

CB

And do you think part of that is because of your age? You're very young.

00:10:29

EJ

Yes, absolutely, because it's not uncommon, but it is fairly untypical because Parkinson's, at the end of the day, is known as the old men's disease. If you look at all the graphics or medical leaflets, they all have the shaking old man standing there, a little man stopped over, grey hair, walking stick. And that's a stereotype. And we're trying to break that.

CB

It's not everybody's reality, is it?

EJ

No, absolutely not. I know a lot of people around me. There's a lot of people that I know from social media. They're all young. They're all young with small kids, and obviously it's affecting them a whole lot differently than it would a 60-, 70-, 80-year-old as well.

SC-R

I find that quite interesting because if you think about some of the people who are in the public eye, who I think about when we think about Parkinson's, we are thinking about middle-aged to older men. I can't really think of a woman or a female that's in the public eye that has come out in terms of saying that they have Parkinson's. Michael J Fox or Ozzy Osbourne would be two that come to mind.

I find that fascinating, especially given it's a neurological condition that sounds like it's hard to access an assessment for that.

EJ

Yes. You're right in the fact of saying there's very few women. Thinking about it now, I don't think that there are any women in the public eye that I know of.

00:12:05

I know that there's a lot with other conditions such as MS. There have been a few recently. But certainly, younger people, you wouldn't... I know Michael J Fox was diagnosed very young, but he also hid it for very long because of the whole stigma attached to it and he didn't want it to ruin his career.

So, ultimately, no, there is nobody really young in the picture at the moment. That's what we're trying to kind of replace.

CB

Yes, because there will be people affected.

EJ

Absolutely, absolutely. People are getting younger and younger and there's more and more younger people, so we're going to see it an awful lot more often.

CB

So, dopamine is the happy hormone. I think of dopamine when I think about when I'm feeling happy and I laugh or I've done some exercise, quite rarely. I remember that feeling of, oh, I feel really great. But I hadn't had any understanding at all that this was what Parkinson's was linked to and that that was happening with the cells. Can you tell us, what else does it do to our bodies or for our bodies?

EJ

Okay. I have my notes. I'm going to need to look at those because I don't remember it all.

CB

You're not a doctor.

00:13:26

EJ

No, exactly. So, dopamine is one of the neurotransmitters that coordinate nerve and muscle cells involved in movement. So, in your brain you want to move, and your brain sends the signals, like your arm moves. So, the area in your brain that facilitates all this doesn't have enough dopamine, which means that the brain can't send that signal properly, which means that the area of your body that it's trying to contact is basically malfunctioning.

So, if you think about a robot which has some wires loose, it's just going in all sorts of directions rather than going where it's supposed to go, that's basically what dopamine is. It's just the signal isn't quite right anymore.

Therefore, you have the tremors or muscle stiffness or jerky movements. Some people have jerky movements. So, that's all the different ways it can affect the movement itself. But then dopamine is also responsible for controlling mood, which is where your mental health issues then come in.

It affects your concentration, feelings of motivation, satisfaction, pleasure, all those happy feelings. Obviously, you're lacking your happy hormone, therefore your mental health issues, your apathy, come into play then. There's evidence actually, which I find very interesting, that suggests that you show symptoms of Parkinson's when you've already lost about 60% to 80% of your dopamine-producing cells.

So, putting that into context, four years ago when I first started showing symptoms, I was already down more than half of what I should have. I don't even want to know what I'm at right now.

CB That's a significant amount.

00:15:19

EJ

Yes. So, that's where it starts. I think the very earliest you would have your symptoms is at least 50% of loss. So, dopamine does an awful lot, and obviously the loss of it just causes a lot of various things to malfunction then.

CB

A person question. You don't have to answer it. In spite of all of the pain that you're physically under, do you feel a significant decrease in just your general happiness?

EJ

Yes. I find it very hard to get my happy feelings together so that my family isn't affected, because obviously you want to go and enjoy your kids. You want to spend time with them. You want to spend time with your family and friends. You want to do the things that you enjoy doing. And it takes an awful lot of concentration and focus on getting all your energy together to do that.

So, I think I've said it before to someone, you know when you have a deficiency in some vitamin or mineral and you feel kind of, I'm missing something, you're craving something, that's what it's like. I'm constantly feeling like I'm craving something, and it's just the lack of dopamine in your brain because you need it and you can't get it.

CB

You're taking medication, aren't you? And that's to try and help replace some of the dopamine.

EJ

Yes.

CB

But that's for your physical symptoms as well as...?

00:16:55

EJ



Yes, that would be for the physical symptoms. I'm taking levodopa, which is the step before it turns into dopamine and your body then turns it into dopamine. So I'm taking that, and I'm also taking a dopamine agonist called Neupro. It's a little parcel that you stick on your arm or on your leg or somewhere, and that helps absorb the dopamine I think and also helps whatever dopamine you have left in your body work better.

CB

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SC-R

You created a really interesting segue there about family because, obviously, this has a massive impact on you physically and emotionally. But can you describe the impact your health has had on your family and maybe work and social life?

EJ

Well, they always say, don't let it control your life. It's very difficult to not let it control your life because, ultimately, you schedule everything around your medication. I'm taking medication five times a day. You're not supposed to eat within roughly an hour, 30 minutes to an hour before and afterwards because protein can impact the absorption of the levodopa in your body.

So, obviously, you're planning around five times taking medication, when can you eat, when can I drive, when am I well enough to do this. So, everything just seems to be impacted alone by my medication schedule. And then, obviously, with that comes fluctuating moods and fluctuating physical capabilities because you take something, your dopamine spikes, everything works.

00:18:45

Sometimes things work too well, which means then that's where sometimes the dystonia kicks in. You can have then these jerky movements when you have too much. Then you have about an hour or so in between of doses where you're working well, so you try to do all the things that you need to do, all the things that you want to do because you're working, or your body's functioning, and then it goes down again and then you're waiting for your next medication.

So it does run an awful lot of your daily routine. So it's very difficult to not let it ruin everything. There's then obviously things, because of the constant pain and the cramping of your body, I don't sit down on the floor anymore and play with my kids. And they notice that. So, it's quite difficult to explain to them why I don't do that. My youngest is madly into video games. I can't with my right hand control the little joystick thingy, so I don't play video games with him anymore.

So it just impacts a lot of things. I find it very hard to get motivated to meet friends because getting there is a struggle. So I sometimes find somebody who

can give me a lift or find other ways to get there. I don't like going out. I like being out. I don't like the leadup to it because it takes a lot of mental energy to do all these things. So, yes, it's difficult to coordinate all the things.

And work, I don't work fulltime. I can't work fulltime. I can't do the job that I have most recently trained because I can't use my fingers anymore. I work in a supermarket now two days a week, which is really, really good because I'm keeping active, I'm keeping busy. You're meant to just keep moving to try and slow the progression, so work is good. But then again, it's only two days a week and then I spend two days recovering from those two days of work.

00:20:46

SC-R

And do you find, you don't have to answer this, but do you find your workplace or who you work for, are they quite accommodating about potential things that might happen during your day?

EJ

Yes. They're absolutely brilliant. They're really, really good. They have known from day one that I have Parkinson's. I've said it in the interview because you need to fill out some personnel form, and I can't write because it's my right hand that's affected. So, filling out that I was like, no, I need to tell them straightaway, and they were really, really accommodating with everything. My line manager constantly checks in to make sure that everything is fine.

There are other accommodations made in work to make sure that I don't fall through the cracks because of that. So they're really, really good.

CB

Do you say that's the policy of the company you work for? Is it just that you have a great manager?

EJ

No, it is company policy. I know there are a few other colleagues as well who have conditions, and they have the same accommodations made. So, that is company policy. I don't know if it's standard procedure that every company has to do these things.

00:22:01

I know that certain accommodations need to be made at the workplace, but I don't know if they have to go as far as my company does, because I feel like they're really going above and beyond, whereas at previous employers before I got diagnosed, it was very discouraged, being sick, and just come in even though you're sick and you're not feeling well, whereas now it's, if you don't feel well,

please go home or please don't come in. So they're very good.

SC-R

That's good.

CB

And it's interesting how you were saying... Flip. Brain fog. This is getting so bad. I forgot what I was going to say, but I thought of something else to do with brain fog.

SC-R

Chantal, you're as bad as me, honestly. I have a neurological condition as well, and I do get brain fog, proper brain fog. I was going to say your age, but you're only 22, so you can't have brain fog at 22.

CB

Well, it's actually what I was going to talk about. Basically, perimenopause, menopause, hormones going everywhere, plus Parkinson's. Do you think that you've started to feel an impact from that yet, or it's too early to tell?

EJ

I don't know, to be honest, because I know that definitely the hormones will impact how, for example, my medication works because I've noticed the week around my period, I might as well not take it.

00:23:34

CB

Oh, really?

EJ

Yes, because my medication just doesn't work at that time. So, that definitely has an impact. I know that there is a risk of earlier menopause, therefore obviously earlier perimenopause. And I have spoken to my doctor about early perimenopause, and it's difficult to tell whether you have it or not because there are these tests, but they're not really conclusive. But I think it seems to be starting.

CB

Just about thing for you to contend with.

EJ

Yes, just. Yes, throw it in the mix.

CB

It's come back to me now. It was about keeping agile and working. It's good for you, but then you do get a payback and you have to rest.

EJ

Well, that's the thing. And it's difficult because the thing that is good for me is the movement and all the gross motor skills, which I'm good at, because fine motor skills, might as well not even bother at this point. But then, yes, you do pay the price of being really tired. But then you can't sit down and rest because your body doesn't like it when you sit.

There have been times where I would go for a walk at one o'clock in the morning because I can't sit down, I can't go to sleep, so rather than going insane with the pains, I'd rather go for a walk and feel better. You're tired still, but at least feel better.

00:25:06

CB

You are listening to The Sunflower Conversations. Remember to hit subscribe. I've heard of dystonia before. Have you, Scott?

SC-R

No, I've never heard of it. Never heard of it.

EJ

Dystonia is a condition in its own right as well, but it's also a side-effect of Parkinson's. I think dystonia in itself is a whole other thing. It's a lot worse I think that just the dystonia that you get with Parkinson's. But I'm not very well versed in that.

CB

It's not very well known about, I don't think, is it? I used to work for somebody who had it, and for a period of time his head was at a right angle. He could not straighten it, and he was in a lot of pain, a lot of pain.

EJ

Yes, it does hurt. I've done this experiment with my father where I told him how to contort his body in order to feel that kind of tense pain, and he's like, no, I can't do that. It is very difficult to do and it hurts.

CB

Yes. So, what support is there available?

EJ

Well, you have your medical treatment, which isn't very advanced. It hasn't really come a long way since about the 80s, I think. So you have your medical treatment of different kinds of medications. You have your dopamine agonists, which help the remaining dopamine work a bit better. You have your levodopa which adds dopamine to the body. There are a few other types of medication that I'm not very familiar with because I haven't taken them.

00:26:55

There are different methods of taking the dopamine. I'm currently just taking the pills, but once you progress a bit more and need a more steady level of dopamine, there's pumps, similar to an insulin pump, which goes through a stoma right into your gut to be taken quicker. It is actually quite cool.

So it goes straight into your gut, which means it goes to your brain a lot quicker and you have a good level of dopamine coming into your body, rather than having the spikes up and down with the pills.

Then you have your slightly more invasive treatment, which is deep brain stimulation, where you have electrodes placed into your brain and you get a pacemaker that's connected to it, and that tries to control your symptoms a bit better. It is fairly successful. I think the success rate of the surgery, the surgery actually works really, is about 90%, I think.

It is reversible, fairly low risk as well, as risky as brain surgery gets, but fairly low risk in the grand scheme of things. So, that would be a medical treatment, but other than that, you have physio. I do a private physio. You can get referred for physio in Ireland but the wait list is about... I think I'm on the wait list, and it's taking at least 12 months to get seen. So you have private physio, which is expensive.

And then you have your voluntary support groups through charities or groups that might have set up their own meetings, and the internet, social media. That's kind of what you have.

00:28:47

CB

I hope doesn't sound really silly, but just things like a sauna, would something like a sauna help to kind of relax the muscles, or a jacuzzi, to massage the muscles. Would that give it relief, do you think?

EJ

I haven't tried that yet. Now, I do have a massager, the big Yokes [?] that you can

massage your own back with. I do have that. It's quite nice sometimes. What I also have is a TENS machine. The first time I heard about it was when I was pregnant. So I've used it when I was in labour, and it can be good for pains. I sometimes use it for leg pain.

But I don't think it goes deep enough for me. It's more the surface muscular pain, whereas I think for me, especially with it in my leg... Now, I have to say to that as well, I have I think about six or seven slipped discs in my back, two in the lower spine and four or five in my neck.

CB

Good grief.

EJ

That was actually the first symptom of the Parkinson's, but I didn't know at the time that it would be a symptom of the Parkinson's. And there's osteoarthritis in there as well, and that seems to compress nerves in my leg, which causes some of the leg pain. And that obviously doesn't get touched with the TENS machine because that's more for the muscular pain.

00:30:17

SC-R

There's a lot going on. It's not just about that Parkinson's bit, is it? When you hear the word Parkinson's disease, you just think of a neurological condition, don't you? I know in the beginning you said everybody's different and how it affects them, but to have all these things added on to the diagnosis of Parkinson's, that's just baffling to me in terms of how you cope with that. The fact that you're quite happy and bubbly sitting chatting to us, I'm sure it's not like that all the time. I'm sure it's not.

EJ

No.

SC-R

Your social media posts and trying to bring a little bit of humour in, there must be days where you just think, oh, I cannot be bothered with this today.

EJ

Oh, absolutely.

SC-R

Just let me disappear into the forest and just keep walking.

EJ

Yes. There have definitely been days where I was like, no, I'm not taking my medication anymore, I'm sick of being sick. So there have definitely been days, especially the patch that I'm taking. It's not a huge deal to put on the patch because it's a two-second thing. You take the cover off and you slap it on and you rub it in, and you're done.

But there have been days where I was like, I can't, it's such a huge effort to put that thing on that I'm just not going to today. And obviously, you feel the effects of it then.

00:31:39

But there have been days where I'm just not going to take my medication because I just don't want to anymore. So, yes, it's not all fun and games, but we need to try and make our best out of it because it is lifelong, at the end of the day, and I still hopefully have a good amount of years ahead of me.

CB

That's what you said, is people don't die from Parkinson's.

EJ

No, that's the thing. People don't die from Parkinson's. They die with Parkinson's, and sometimes of the side-effects of things that happen. So you can have a nasty fall.

There is a thing called freezing, where I've had it happen only once, luckily, and where your body just stops walking. So, imagine you're mid-walk. I was at the time skipping down the steps at work and my legs were just like, no, not doing it anymore. But obviously, your body is just caught in the momentum, and so you get a lot of falls. I see online a lot of people comparing how many stitches they've had this week, and fractures.

I know Michael J Fox has spoken about it, where he's had at one time his shoulder fractured and his arm and his wrist and his cheekbone and all those things, just from a fall because of freezing or because of poor gait.

CB

So there's a lot to watch out for.

00:33:01

EJ

Yes, that's the thing. The picture that most people will know about of Parkinson's is the person shaking, but there's a million things. The tip of the iceberg is all your

primary symptoms, and then you have whatever is under the surface is all of the other stuff that comes with it.

CB

I guess that brings us on to the Sunflower. I'm interested to know, how did you discover it?

EJ

I actually don't remember. I can't tell you that.

CB

Just make something up.

EJ

No, I probably saw it online because that's where you come across most things. So I probably saw it online. I've seen a lot of parents with kids on the spectrum talk about it. So I've seen them using it for travelling, so I looked into it, and I do travel a fair amount. I'm from Germany, so I will be back and forth.

So I've used it a lot travelling last year, and I've had a really good experience with it. Airport staff are amazing, because they all recognise it. They all seem to be trained. Well, at least at Dublin airport that's the experience that I've had. You get moved into shorter queues. They don't rush you at security where it's notorious for quick in and out. And it makes for such an easier time when you're already stressed with the travel.

And then recently I've also been wearing it in work. I've seen other colleagues wear it in work. Some would be affected themselves by something. Others are just I think trained in how to handle somebody with the lanyard.

00:34:56

And it's just nice to see that there's other people because with a hidden disability you don't obviously see somebody else who might be going through the same thing or something similar. So it's just nice to see somebody. It's like a little secret handshake, kind of thing, just to see somebody else and you just feel less alone genuinely, as cliché as it might sound, but that's genuinely what it is.

CB

You can probably align yourself with some of those things that Eve has said, can't you, Scott?

SC-R

Absolutely. Absolutely. And I'm wearing my Supporters lanyard today, but when I'm out and about, I would normally wear my Sunflower lanyard or my wristband,



which probably confuses people, wearing both of them, but certainly I do love it when you're out and about and you do see somebody with it. It's almost like you want to go up to them and go, hi. You don't. Well, I don't. I don't know about you, Eve, but I don't, just in case they might think I'm quite weird.

But I do find it interesting if you go into a retail store and you see staff members wearing a Sunflower lanyard, because it just makes you think, actually, they're aware of it, they know what it means, because the whole store staff aren't wearing them, so therefore this person has either chosen to wear it or they've had permission from their management to wear it.

00:36:26

And I think that just gives you that little piece of mind that actually, if you're in that place, that specific place, in a retail environment, that if you need help... You'd probably clock where they are, where they're working, because I do that. If I see someone with a Sunflower lanyard on them, right, they're in that aisle. They could move, of course, but if I'm in and out of a shop, then I know where they are. So it's great to just have that kind of thing in your head that says, if something goes wrong, I can just run back.

EJ

Yes, that's the thing. It's just nice to have, because I know within my shop there is there definitely one person who's actually properly trained in how to respond to people that might approach them or respond to people that they might see as customers walking around the shop, but there are definitely other staff that would be affected themselves and therefore obviously also know what it means.

CB

I think also what you're talking about here, being in this retail environment, it also goes to show that just because you have a disability doesn't mean that you can't contribute to society, have a purpose, be part of a team. And I think that's another thing as well. Obviously, wearing it is an absolutely personal choice. Nobody has to know that you have a disability if you don't want them to.

But I think that it just brings it out into the open, that the statistics are really high of how many people have a disability, and when you see people, I think, and if you know what the Sunflower means, it just makes you a little bit more conscious and lots of people do have non-visible conditions and disabilities.

EJ

That's the thing. I've heard a lot of talk as well about, for example, blue badge holders that, oh, they look fine, why do they have a blue badge?

00:38:20

It's like, yes, just because they look fine, and they might feel fine in the moment,

but they might not feel fine coming out of the shop and they might not feel fine walking for five metres and then suddenly not being okay or maybe needing to go back to the car fairly quickly.

And it's just really tricky to judge someone just based on what you see because not everybody who might have an issue with, let's say, walking longer distances needs a wheelchair or needs a walking cane or something like that. So you always need to be conscious of how your condition might change, even in the space of five minutes.

SC-R

So, why is it important to you, Eve, to share your story on this platform?

EJ

Well, for me, sharing altogether has generally two aspects. One, it's definitely breaking down stereotypes, get away from the old man, get away from the alcoholic type thing as well. I've heard that as well. Oh, have you been drinking, or things like that. So, definitely it's breaking down stereotypes, that there are an awful lot of younger people, a lot of people in their 30s, sometimes even younger than that.

And the other one, which is probably more my social media rather than doing something like this here, is literally just venting, venting and vocalising what's currently going on, especially when it's three o'clock in the morning, nobody's awake. But there's always somebody online. And even if there's nobody online, I can talk to the phone, I can get it out there, and more often than not, somebody will respond and be like, this is actually what's currently going on with me as well.

00:40:05

So it's just blow off steam, just get that energy out of your body, because otherwise I know it's staying inside and it's getting pent up, and then somebody else will hear from it, and it's better to just get it out straightaway.

CB

That's a great use of social media.

SC

I was just going to say, because we hear so much negatives. For that to be therapeutic for you, especially like you say at three or four in the morning, that's a great way to just get it out there. And also, someone's going to pick it up the next day, even if nobody picks it up at four A.M. You've got it out of your system, but you're also informing people and educating people as to what you've gone through.

EJ

Yes, or just help other people as well. So I would share something and be like, oh, this is what just helped me in this situation. Let's say a pair of kitchen scissors, the big kitchen shears. Rather than using a cutter or a knife to cut your pizza, you just chop it up with scissors. And there's always somebody who it's helped, and if it's one person, that's one person that's struggling less with something.

So, yes, it's definitely good. And then, obviously, you'll see yourself as well, somebody else might be online and sharing something. It's like, okay, I understand this, I feel it, because it's very difficult explaining to let's say your friends, your family, how you're feeling, but they don't truly understand it, and obviously, there's no blame to that because how can they understand it?

00:41:28

But just to see that there's somebody else out there who gets exactly what's going on right now just validates the fact that I am actually feeling this way and I'm not overreacting.

CB

How can people find you? I assume your socials are open.

EJ

Yes. Oh, absolutely. I am on Instagram and TikTok. My handle is @pd\_and\_me.

CB

Okay. So, if you send that to me, we'll include it in the show notes.

EJ

Yes, please do.

CB

Well, Eve, you have been a wonderful guest, and Scott, you've been a wonderful cohost. But more importantly, Eve, seriously, thank you so much. We have as a company been wanting to cover Parkinson's since I joined, and I was really happy. How I found you was through one of your videos that you made and you had the Sunflower lanyard on.

And so, I can't thank you enough for doing that, for also championing, I can't say that word, celebrating. Can't say it, championing. Anyway, that, doing that for the sunflower. But also, yes, just giving people that connection with Parkinson's so that they too can vent and also share their worries and their achievements. So, yes, thanks.

00:43:00

EJ

Thank you very much for having me. I really, really appreciate the opportunity.

CB

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner. If you enjoyed this podcast, please share it. Leave a rating and review to help raise awareness of nonvisible disabilities and the Hidden Disabilities Sunflower. You can also follow and subscribe to The Sunflower Conversations podcast.

VO

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