Postural Tachycardia Syndrome (PoTS) with Jasmeet Kaur and Helen Eftekhari, PoTS UK

Speaker 1:

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

Chantal Boyle:

Hi, I'm Chantal, and joining me today is Helen Eftekhari, who is a specialist nurse in postural orthostatic tachycardia syndrome, also known as POTS, and Jasmeet Kaur, who has lived experience of the health condition. We will be referring to it as POTS as we progress through the podcast, as it's quite a long tongue twister for me. So ladies, how are you today?

Helen Eftekhari:

Good, thank you.

Jasmeet Kaur:

Well, thank you. Excited to be having this conversation.

Chantal Boyle:

Yeah, it's a good one. We've had a lot of sunflower wearers get in touch around this health condition, so I think it's really important and I'm excited to finally be able to record with you both and find out a bit more about it.

Helen, can you start off, what is POTS and what effects does it have on patients?

Helen Eftekhari:

Wow, that's a really long question to answer Chantal, and I'm sure we'll go through more as we go through the session.

POTS stands for the postural, so that's the standing up part. Orthostatic also relates to how your body adjusts to the upright position, I'll go through that in a minute. Tachycardia is an abnormally fast heart rate, and that's in the response to standing. And syndrome because there's a whole number of different types of symptoms and effects that people can experience, and it can vary from individual to individual.

At the background of POTS is we all have something called an autonomic nervous system. Autonomic means automatic. It's a system in our body that we don't think about. So we don't think about, we stand up, we don't think automatically think, "How do we adjust our blood pressure? How do we adjust our heart rate?" Our body naturally should do that.

Then there's lots of different parts of the autonomic nervous system. For instance, your gut, how food moves through your gut system and how you go to the toilet. We don't think about that, that's an automatic function of the body, same as the way when we breathe. That's an automatic function. So that autonomic, automatic nervous system feeds into lots and lots of different parts of the body, in fact all over the body. And consequently people, with POTS get a diagnosis because of looking at those specific heart rate and blood pressure changes in relation to standing, and that's really important. It's not just an abnormal heart rate, that can be from lots of causes, it's very specifically the standing up response that is quite exaggerated and abnormal. And as a consequence, depending on what other types of systems are affected, people can present with other types of symptoms as well.

There are lots of things that people can have. Some people faint, some people are dizzy, some people are very lightheaded. Some people out there might say, "Well, so what? You get a bit dizzy and lightheaded, what does that matter?" Well actually, if you're just standing up to make a cup of a tea and you're feeling really dizzy and lightheaded, and you have to sit down and you haven't got the energy to move further, that can have a huge, significant impact on your life. And those few symptoms I've mentioned, POTS have lots and lots of other symptoms as well.

Chantal Boyle:

Yeah, I can see that. My gosh. So that's affecting every part of the body really, isn't it? So how common is it and are there any statistics surrounding it?

Helen Eftekhari:

So we haven't got any specific statistics for the UK. The American Dysautonomia International group say there's probably about one to 3 million Americans with POTS, which is quite a lot. Some of the smaller studies have suggested that around 0.2% the population.

I think what most people in POTS UK as well would say is that people with... POTS is probably quite an underdiagnosed condition and a lot more common than we think. So people think it's quite rare because they haven't heard of it. It's just that we haven't got the awareness out there yet about POTS.

Chantal Boyle:

Yeah, that's interesting because as I mentioned at the beginning, a lot of people have been in touch with us about this, and as I mentioned, I hadn't heard of it before. So do you think there will be studies into finding out actually, what is the prevalence of it in the UK? Is POTS UK quite a new charity? Is that why that hasn't been done?

Helen Eftekhari:

POTS UK, it's great. POTS UK has been around since I think about 2010. There about, give or take a couple of years. And it started out with a small number of individuals and has grown since then. And does fantastic work, but because things are so limited and research can cost quite a lot of funding actually, we haven't got any specific studies that I'm aware of that are out there looking at what we call epidemiology or how common is that?

Chantal Boyle:

Yes.

Helen Eftekhari:

But I'm sure there'll be studies in the future, where we do need to look at that. If we know it's more common then we can get more research.

Chantal Boyle:

That's right.

Helen Eftekhari:

Then people can get better supported, because there's more awareness.

Chantal Boyle:

Yeah. And Jasmeet, how long have you had POTS? When did it all begin for you?

Jasmeet Kaur:

I had my official diagnosis in 2019. I was symptomatic probably for about 12 months before that, officially, so seeing doctors. But I recognise my privilege; 12 months is very quick in the grand scheme of those of us that have POTS. It normally takes about nine years, that's what research is currently telling us.

Chantal Boyle:

Goodness, that's a long time to not know.

Jasmeet Kaur:

Really long time of seeing doctors and that experience of misdiagnosis or pushback or even not getting appointments because physically, outwardly you might look absolutely fine, but as Helen said, there's so much stuff going on with the nervous system.

So yeah, it was a process of 12 months for me. So since 2019. My journey began just as we were going into lockdown, I guess.

Chantal Boyle:

So building up to 2019, you said you had been symptomatic. What kind of symptoms were you experiencing?

Jasmeet Kaur:

As soon as I was on my feet there was intense nausea. Intense, and the only way that I could get through it was hunching over. And I realise now that was my body naturally, very smart, very cleverly as all our bodies are, trying to level my head with my heart.

Chantal Boyle:

Yes, of course.

Jasmeet Kaur:

And I had a lot of issues with eating. There came to a point where I just could not digest anymore. Soon as anything went into my mouth, my body was just absolutely chaotic. That's the only way I can describe it to you. I was passing out quite frequently as well, and I was injuring myself when I was passing out. As Helen said, the dizziness, my thought pattern was definitely shifting. I was having a lot of brain fog. Also affecting my vision, particularly my left eye and as Helen said as well, my heart rate was just through the roof and I could feel it constantly, even when I was sleeping, it was waking me up out of my sleep and subsequently I was having a lot of chest pain because of that as well.

And then as Helen said, because it affects so many systems in your body, I think pretty much every single one of my systems took a hit and eventually I couldn't balance anymore either. So I was kind of lost in space and lost in time, if you will. And that affected my walking. And so the tests went away from neurological and into cardiac testing. And that's when I got my answer, my diagnosis.

Chantal Boyle:

It sounds a bit like one of those kind of toys where something spins inside of another sort of circle, and so it's sort of spinning in all different directions so that you can't get your equilibrium, how you've just described it sounds...

Jasmeet Kaur:

Yeah, that's exactly how it feels. I can't think of right now a better description, Chantal, but yeah, that is exactly how it feels.

Chantal Boyle:

Do you feel like you're going to have a heart attack when your heart's going like that?

Jasmeet Kaur:

Sometimes I do. I've managed to get myself to a point of mentally talking my body down when it's really bad, and when it's really sudden. And especially when I'm alone, I do feel like that. I absolutely do feel like that. And happens frequently, but interestingly but also sadly, that fear has not gone away. I know what's happening with my body, but because it's so intense when it happens, you just kind of go into that mode of fear and panic, which I know doesn't help symptoms. So I try to talk myself down, but it's much easier said than done. Much easier said than done.

Chantal Boyle:

So is that a risk factor, Helen? Can you actually have a heart attack?

Helen Eftekhari:

No, you can't have a heart attack with POTS, and even though we see POTS in a lot of cardiac... In clinics, and it's not a cardiologist that diagnosed POTS, although not exclusively, there are other clinicians that see people with POTS, but I would say mostly it's cardiologists. It is not a traditional heart problem.

So the traditional heart problems are heart failure, where the heart doesn't work effectively and efficiently, or blockages in the arteries which cause heart attacks or electrical disturbances in the heart. This is very different because it's not related to the structure and the underlying processes within the heart, it's related to how the automatic nervous system responds to things, and that's what makes it quite tricky.

One of the things I wanted to say is actually I think Jasmeet makes a really good point around how the symptoms feel and that racing of the heart rate, a lot of people really, really worry about it. And I think, quite understandably, people's go to thing is is it a heart attack? And we know it's not a heart attack, and we know it's not going to lead to a heart attack, and there's no evidence around that. So there are no published studies looking at that picked this up at all over the years. However, it can be very scary.

And although I think that thing that Jasmeet brought out around the misdiagnosis of POTS, or being told, "You have got other things." Like what's really common is people say, "Well you're just anxious." So symptoms of POTS can feel like anxiety, you can become anxious because you are living with a condition that's having a really bad impact on your quality of life and what you're able to do. And people are saying to you, "Well, I think it's a bit of anxiety," and you think, "But there really is something wrong and I can't explain it." So because of all of that, then that makes you anxious. After, then, really hard to tease out. You often get the POTS first and then anxiety for a whole number of other issues.

Chantal Boyle:

It's a self-fulfilling prophecy because you have got something to be anxious about, but nobody's recognized what that is.

Helen Eftekhari:

And that length of diagnosis that Jasmeet mentioned, the nine years, and it varies for people. I think probably over the past 10 years, due to the work of, say, POTS UK and different clinicians that the awareness around POTS has gotten a lot better. But still, there's a lack of awareness, and not just in clinicians, but I think also in the general public.

So if I said to you, or Jasmeet said to you, "I've got really bad asthma." You may not understand everything about asthma, but you might say, "Well actually that sounds like it could have quite big, bad impact on her." But in fact if you said, "I've actually got POTS>" you might actually say, "What's that?" So actually this video's invaluable for raising that awareness.

Chantal Boyle:

Yeah. Yes, I really hope so. And so you have spoken about symptoms and what have you, but let's just sort of go back a little bit more. When should somebody, what kind of things would they be experiencing to think, symptom wise, "I think I need to seek a diagnosis that maybe is beyond 'I'm not anxious'"?

Helen Eftekhari:

So I think if you often get consistent... As Jasmeet was saying, you got all these types of different symptoms, particularly if you're standing up, you're getting dizzy and light-headed.

People use a lot of Fitbits these days and there are good things about using Fitbits, and not so good things about them. So the good things about using Fitbits, you can actually check and see what your heart rate response to standing is at home. And it can give you an idea and a clue to go to your doctor and say, "Well actually my heart rate when I'm resting is about 90 or 100. when I'm standing up, within a couple of minutes, it's going up to 140, 150." That's abnormal.

If it's just that you've got a fast resting heart rate, that's not necessarily abnormal and that's where you need to go and see a clinician to get them to look through and do some testing to see if there's anything else that could happen with that.

Usually also people often after a viral illness can get symptoms, because it can... We don't understand the mechanisms behind it, but it can set off this process in the autonomic nervous system. But you probably need at least three months after a viral illness before you start thinking about that.

Chantal Boyle:

So we aren't 100% sure that it's a postviral infection which causes POTS? It's possible, but it's not the only way or reason that you may develop it?

Helen Eftekhari:

Yeah. So you can get them postviral, and we do see that quite a bit. So there's some emerging evidence around POTS and long COVID. There are other things. So we know there's some associated conditions. We don't understand all the processes behind it, but we know there's associated conditions with joint hypermobility, a condition called Ehler-Danlos syndrome. And there's some very emerging data, and not well understood, around people that have multiple allergies as well. So we don't understand everything about it, but we do see it and you see it very commonly in practice.

Chantal Boyle:

So-

Jasmeet Kaur:

Wanted to add there, Chantal, sorry. I know Helen has listed the physical ailments, but there is also emerging research to show trauma, any kind of trauma to the body which affects all of your systems in that sense, can also bring on a POTS diagnosis.

For me, it wasn't postviral at all, it was the backend of an adverse reaction to a medication and my body just never reset itself. So me and my consultant, we often do the, "What if?" Sometimes it just helps to talk it out with someone and we wonder if I'd never had that reaction, would I get the diagnosis? Would my life have paused, so to speak, or would I just never have had the diagnosis? Would it have come out eventually?

Like Helen said, we just don't know about the mechanisms yet, but any kind of significant change in the body can bring on that POTS diagnosis.

Chantal Boyle:

And it's not neurological. So it wouldn't be necessarily a traumatic event that was non-physical. It would have to be something where your body... affected your physiology. Is that the right way to describe it?

Jasmeet Kaur:

I mean it depends how you like to approach it, but again, emerging research is all about the mind and the body connection. So even if there is something traumatic that you think would only impact a person's mental health, but of course that's going to have a knock on effect to the body as well. As we know, if you've got a little bit of anxiety in the morning, you know might have an upset tummy, et cetera, and there is emerging research to show that that could be one of the pathways to your body just flipping, I guess, so to speak. Because it does feel like it just flips, it goes upside down and it never goes back to what it was.

And then there's much more coming out about the mind body connection. I think it's brilliant. I think it's really helpful as a way to understand symptoms and also as a way to manage symptoms as well.

Chantal Boyle:

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So why is chronic fatigue such a feature of the condition and are there ways that it can be managed? Jasmeet, you're employed, you've got a really responsible role as a teacher, how do you balance the fatigue that you experience?

Jasmeet Kaur:

I'm not sure that I do Chantal.

Chantal Boyle:

Yeah.

Jasmeet Kaur:

And that's my honest opinion. I'm not sure that I do still. I'm hopeful that I will, soon, one day, but chronic fatigue is always my best friend. No matter what I do, no matter what I try. No matter the protocols that I try, the pacing, the chunking, the resting, it's just the shadow. It's really difficult.

I think it's probably one of the most difficult things because when I explain to people that I'm fatigued, they kind of say, "Oh yeah, me too, I didn't sleep well." And it's like no, no, no, no, no, no, no, no, no, it's completely different. It's a different feeling. It's a completely different feeling. I can have a whole night of sleep and I'm still waking up exhausted and drained constantly. And that's obviously because of the mechanisms in the body and how sleep is affected by the autonomic nervous system or the other way around so to speak. And the way that I manage it mostly is by being absolutely cutthroat, and I have to be. And it's hard, it's really, really mentally, emotionally and spiritually hard to be that cutthroat and to say, "Today, I can't. I can't human today, I can't socialise today, I just can't do it."

The way I manage it is a lot of me time. I get really overstimulated by doing things and speaking and getting dressed and then eating and just being a functioning member of society. I need a lot of downtime.

It's really, really hard to explain to people, and I hope Helen can maybe give us a way to explain it to people. It's so difficult, Chantal, because outwardly you look okay, you can do your hair and get dressed and put on a little bit of makeup and you won't be able to tell. But it's one of the most difficult things to explain to people that I'm just exhausted and I just can't, because then they say, "But you look fine," and you're like, "But I'm not fine."

Chantal Boyle:

Nothing a power nap is going to fix.

Jasmeet Kaur:

It's like being underwater and walking through treacle.

Chantal Boyle:

Oh gosh.

Jasmeet Kaur:

Or walking through mud, and some days it's just... It's relentless. And then there are obviously things that affect it more. So if you are stressed or if you haven't eaten properly or if you are on your period or you are ovulating, and all of these things are affecting it, the weather's changing and-

Chantal Boyle:

The weather has an affect.

Jasmeet Kaur:

Yeah, I'm going to be much more tired and it's not something that I've managed yet. I've found some techniques to get me through. I'm not quite there yet.

Chantal Boyle:

I would've thought with the weather changing, with it being warmer and the body not needing as to use as much fuel to keep warm, you would've had a bit less of the fatigue during the summer. But no, Helen's shaking her head.

Helen Eftekhari:

One of the crucial mechanisms around POTS is that you often get a lot of pooling of blood in the legs. And so there are mechanisms within the heart that sense that you haven't got quite that blood volume in the center of the body, in the head, effusing all the organs in your chest and upper body area. So as a consequence the heart beats really, really fast. So we understand that about POTS.

In the summer, and in the heat, what actually happens is you get what we call but vasodilatation, where you get expansion of the blood vessels, as a response to heat. So you actually find most people with POTS really don't like hot summers, but they love cold winters.

Chantal Boyle:

Okay. Okay.

Helen Eftekhari:

And I wanted to come back, Chantal, to a few things that Jasmeet said that I think are really, really important. And the first thing that's really important for people out there to understand is that people with POTS, it's not that they don't want to socialize, actually people with POTS generally want to be quite sociable, but actually it's the condition that's holding them back. Because often, if you end up doing too much on one day, then you really pay the price. And it's not just paying the price for a couple of hours the next morning, you probably pay the price for a few days. So you have to really balance your activities and what you're doing around the condition. So it really dominates a lot of your planning of what you're doing in the day.

The chronic fatigue, again, we don't have a complete understanding of it, however you can well imagine if you're standing up and your heart rate's going quite fast, that's going to make you really exhausted just because it feels like you've run a marathon just by pottering around the kitchen. But even when we put people on drugs to control that heart rate, you still get a lot of people saying that they still feel quite fatigued, maybe better than they were before, but they can still be quite fatigued. And it's probably just to do all with that autonomic nervous system at the background not functioning well. And also I think, as Jasmeet really eloquently talked about, was the sleep and getting sleep disturbances, because our automatic nervous system controls our sleep regulation as well. So you'll often get people with POTS having abnormal sleep patterns and having difficulty with sleep.

So some of the things that can help, Jasmeet talked a bit about pacing, and I don't think it's the whole answer, it can help. So it can help recognising that if you're having a good day, not trying to jam everything into the good day because you know that'll actually set you off for the whole week and you'll just have a continuous run of bad days, and more about learning to manage your energy. And that can sound quite simple, but actually if you've got POTS, or any chronic condition, just doing things like getting up in the morning, getting dressed, having a shower and breakfast, you may have used half your day's energy or a good portion of your day's energy just doing that.

So there's a lot of tactics that people are advised to do or some of the best stuff that we've got at the minute because that's the limitations of where we are with science is around what's called pacing. So just learning to pace your day, learning not to expend all your energy on a good day, not to be unrealistic. I think it's really important that people are kind to themselves. I think because of the lack of awareness and the invisibility, the invisibility that Jasmeet talked about, putting your makeup on and looking quite normal, everyone thinks, "Well what's wrong with you? Why are you using a disabled seat on the bus? You look really normal, you're just being cheeky." And that's not the case.

So living with that invisibility is really hard for people to manage and cope with. And like I said, the lack of awareness. So I think family and friends can really understand that if somebody says no, it's not because they're trying to be rude or unkind or they don't want to socialise, it's probably because they can't socialize.

Chantal Boyle:

And so it's really important your group around you, whether it's your work situation or your social situation or your family, understand what your health journey is, to avoid the misinterpretation of you not participating in events. I mean, have you come across that a lot, Jasmeet, of people perhaps maybe not understanding why you're not joining them for dinner or going to a party or what have you?

Jasmeet Kaur:

Yeah, a lot. A lot. Yeah, a lot. Some of the people that are closest to me in my life still don't understand. And they still think it's just a form of non-support or picking and choosing. Yes, I am picking and choosing, I'm picking and choosing so I can function, because if I say yes to absolutely everything and absolutely everyone, I'm going to be a mess. When you've had a

POTS flare, you'll do anything, absolutely anything, to avoid it because it's horrible. And it is of a detriment to your relationships; family, friends, professional, et cetera. But it is what it is.

And like Helen said, you've got to learn to say that I'm going to be kind to myself, I'm going to honour myself, I'm going to show myself some grace. My body's amazing, it's intelligent, it supports me and in return I've kind of got to protect it as well. Also being from a Punjabi background that chronic illness, non-visible disabilities are not spoken about, we're making some progress but it's not enough. It's much harder to explain to people we don't even have words in the language system for orthostatic or nervous system, et cetera. And that's another battle I face because everything is face value, "Well, you look fine, are you sure you're just not exaggerating?" Or, "You sure you're not anxious?" Or, "She's just depressed." Or... I've heard from many family members that I've just got an eating disorder.

Chantal Boyle:

Oh dear. I mean you're really facing a physical and mental battle, aren't you?

Jasmeet Kaur:

And it's kind of just about knowing which battle to fight and when, and what to just let go of. But yeah, it does have an effect. But also it has such a positive effect as well, because you really see people around you transform their mindsets, transform how they approach things, the language they use with you, and then they start to use that language with themselves and how they're approaching visible or non-visible disabilities. You see that transformation and it's amazing, and you kind of learn who's really there for you and you can nurture those relationships and those friendships.

So yes, there is a negative, but there's also that positive as well. And the biggest thing, and I guess the best thing for me, is I've become my own best friend now. There's no longer that disconnect between me and myself. We've kind of come together now.

Chantal Boyle:

You've got each other's back.

Jasmeet Kaur:

Yeah. And that's invaluable. We talk a lot, I speak a lot, about the negative impact of POTS because it's so impactful, it's life changing, but it's life changing in duality and that positive and that negative as well. So as much as it's exceptionally hard every single day, you do have those pockets of positivity where you're like, "Yes."

Chantal Boyle:

I'm pleased to hear that.

Jasmeet Kaur:

It comes full circle sometimes.

Helen Eftekhari:

I think most people with POTS go through that life change, and the fact this is predominantly a young female profile that we see. And you often imagine, you see people in their prime of life just like Jasmeet, working. And actually Jasmeet, I think you're doing really well. There's a lots of people with POTS that have a lot of struggles working. So just by managing to work, that's probably having quite a big impact on your social ability, because you're probably completely whacked at the end of the day I'm sure.

But you find that a lot of these younger people there, it interrupts schooling. So you find people that might be doing GCSEs, A-levels, they may have been absolutely... In fact, you commonly hear people that were top students all of a sudden can't go to school. Or maybe at university, they've had to drop out or delay their studies. People who were in work and are have been struck out of work. So a lot of people with POTS can't manage with that.

And I think what really is needed is a huge amount of awareness around POTS, because if people go, say, to school and can support, maintain or keep going to school, lot of people will not understand and they'll say, oh... Just like Jasmeet said, they'll say "Oh, it's kind in their head. They're attention seeking." These sorts of really unhelpful, unsupportive comments.

And same as in work, it's very simple things to put in workplace. You can probably support [inaudible 00:32:49]. You can probably support people to a degree, and there's lots of access these days to worker friendly practices and things like that. And I think if there's an awareness of the POTS as a long-term condition, not just something that you know, okay, you got it for a couple of months, now you should be better, because that is not the course. Even the people that do well with POTS, probably takes them a number of years. You can very quickly go down [inaudible 00:33:22], but actually you can get a number of years before those people actually recover. It can be a long journey.

Chantal Boyle:

And you mentioned that you see a lot of young women, so that typically women are affected more than men. And do you think that that has anything to do, as you were talking about, the menstrual cycle and how that has a fluctuation within the body? Is it linked like that? Is that something where we're just not there yet?

Helen Eftekhari:

We're just not there yet.

Chantal Boyle:

Yeah. But some men can have it.

Helen Eftekhari:

Yeah, you do see men that have it. And in the research you would probably say that anywhere from about 80 to 90% of people are women get POTS, and probably 10 to 20% men. And it depends on which clinic you ask and which study's been done, but they're predominantly women. And probably the reason we're seeing it younger now is because we have more awareness. POTS wasn't recognized until 1993, which is actually quite young in medicine, very young. And so POTS UK's been around since, like I said, around 2010 I believe. And so you can imagine that we haven't got the awareness and understanding out there.

Chantal Boyle:

Yeah. And when we were talking about how non-visible it is, nobody would ever know, looking at you Jasmeet, the health struggles that you've been having and experiencing. What do you think about the sunflower in terms of making the invisible visible?

Jasmeet Kaur:

It's life changing, because sometimes when I'm out and about, everything is so much. The body is so much, and because the body is so much the world around me becomes so much, I can't find a voice to advocate for myself. So just having the lanyard, it kind of just takes away that... I wouldn't say the responsibility to myself. It kind of makes it easier. This is me and I do things slowly and I need you to keep your distance, and sometimes I might need support and I appreciate when people ask me if I need support and stuff, but I think it's life changing. And I absolutely love it when I see someone else wearing a sunflower lanyard as well. It's like, yes, me and you, we're in this together and it's normalizing it.

I think so many of us, like Helen was saying, we so badly, we so, so badly just want to do life how everyone else does life and we dream of it and we just can't. It's not that we don't want to, we so, so desperately do. And it's normalising it. It's normalisung that you know what, everybody is different and even having a condition, those of us that have POTS, we are all so different to each other. It's a syndrome, so it affects us differently. And it's a sense of community, it's a sense of unity, takes away a little bit of the shame that you might feel. And I know I felt it when I was first diagnosed. Like Helen said, it totally interrupts your life. So I had a two-year pause, I'd say a two and a half year pause out of life. I wasn't doing anything.

I say I wasn't doing anything. I was looking after my body. I guess the most important job anyone can do. And it just removes that layer of that shame, that isolation. I'm a part of community, I can function in society as well. So I think it's amazing, it's positive, and I would implore anyone who qualifies to definitely get themselves a lanyard. And it's a sunflower and they're so beautiful and lovely and they're so strong. Yeah, I think it's great.

Chantal Boyle:

That's the whole purpose of it. And you mentioned qualifying. There's no qualifying procedure that we ask because, as you've mentioned, there is so many things that people are living with and experiencing that we can't see and we don't understand. It's really very much on the wearer to choose. I think this would really support me in this situation. I'm getting on the bus, I'm going to have to sit down. This will just give people around me a nonverbal way of knowing that there's a reason why I'm sitting here. So we really do try to make it so that it's accessible and not red tape. And the mental health impacts of having POTS, you've spoken at length really about how difficult it's been, Helen, is that something that you deal with a lot in trying to support people with their mental health on their journey with POTS?

Helen Eftekhari:

Yes. I have to say I'm not a mental health practitioner per se, but I think there's a few things that do address mental health issues. The first thing when we see patients is I always validate them and validate their journey. And I think that's really important because people can feel I think, as Jasmeet said, it can feel a very lonely, isolating place when you are feeling lots of symptoms are debilitating and yet at the same time you're being told by healthcare practitioners, "We can't find anything. We don't think there's anything there." And then your family as well on top of it kind of think, well, if the doctor says there's nothing there then there's nothing there. And I think that's a very difficult journey for people. So first thing I would do is validate them, and I think that's quite important in terms of mental health. I've had patients come back to the clinic and just say, "You just listened to me and you knew my story." And that's quite... That really supports them move forward in terms of there is something there, I'm not mad, I can think about moving forward.

I think also understanding around the difference between anxiety and heart rate, symptoms of anxiety and then also understanding the heart rate. So trying to tease that out and that's really, really not easy at times. And then I think also helping people come to terms with the fact that there's a long-term condition and that means that you ask them with any sort of condition that's long term, you have to understand the condition, understand the management, have some acceptance that this is happening, because it's a really difficult thing if you're in the prime of your life and you've got a life plan in your head and then all of a sudden it gets completely disrupted, you think, I thought I was going to be a big high-flyer and do something or do this. Or even just I was going to be a mum, not just a mum. That's really important. That's our most high-flying thing of everything, isn't it? You have these plans and then all of a sudden you can't fulfill that, you're just not capable of it.

So I think partly that comes around understanding POTS as a long term condition. And understanding that there are periods that there's flareups and things like that because that can be quite frightening as well. If I'm having a flareup of the POTS, then people might think, "Is there something else wrong? Does this mean I'm getting really, really bad and I'm going to be really, really sick?" Or just understanding that POTS has a variable nature and that you will have flareups. I think those are quite important in mental health. And then if there's anything more significant, more significant things, we do sometimes advise people to look at... There's the IAP services, which most healthcare areas have now, which is... IAP stands for Improving Access to Psychological therapies, and their counsellor, they will not have an understanding of POTS. So it might be a bit difficult talking through, you often find people with POTS are explaining to counsellors the difference between POTS and anxiety, but they've often got really good top tips around managing things, around trying to stay calm, grounded, which given people's experiences can be quite difficult.

And also psychological therapies for long-term conditions. And I think that's quite important because you get specialist psychological support on a one-to-one basis, which looks not so much as manage your anxiety, manage depression, that sort of thing. It's more around those concepts I talked about about coming to terms with POTS as a condition, that you've got this diagnosis, what this means for your life. And then refocusing your life really not to be so goal centered but to have your values and what is meaning and what is important for you rather than I've got to be on my career step or I've ,got to finish my university. And those sorts of things, making certain that you're very well, that you're grounded.

Chantal Boyle:

So Jasmeet, you presumably have been through most of the things that Helen has talked about, and I noticed that you were saying earlier on when your heart is racing that you try and talk yourself down from that. So do you include a lot of mindfulness in your everyday life?

Jasmeet Kaur:

I do. I do include a lot of mindful practice. I include a lot of meditation and that kind of... not passive meditation, but active meditation, so when you're on the go. A lot of positive self-talk like Helen is saying and not being goal centered. And at the start it was so hard. It was so hard. I'd just landed my dream role at work and I was a couple of months into it and just overnight it was just... it's just gone.

Chantal Boyle:

Yeah, it must have been gutting.

Jasmeet Kaur:

But yeah, like Helen's saying, therapy and the intervention is so helpful. And I'd also like to touch on the fact that there is some stigma around going to therapy and seeking support for your mental health, but it's so helpful and it is so invaluable and if people are struggling with the acceptance side of things, and I know I did, it was so difficult. I know, I see you, I recognise you. I was there as well. Sometimes I'm still there. I go back to that space. But as Helen is saying, moving from the goal centre to the value centre to the quality centre is really helpful.

So yeah, I went through all of that intervention. Took me two or three rounds. I was really lucky that I was given that much support. I recognise my privilege. I know some people depending on, as Helen said before, boroughs and catchments don't get it. I was so privileged. I went through three rounds and yeah, it really, really helped because it's so lonely at the start. So lonely. You're a different person, your body's not the same, your mind's not the same, you are not the same. There's so many what ifs about the future.

Chantal Boyle:

Good, good, good. This is good to hear. And the treatments, Helen, that are available. So there's obviously the mind therapies, it's good to get your brain into good brain health. What other treatments are available to patients that have POTS? You mentioned some medication for heart rate earlier.

Helen Eftekhari:

Yeah. So there's some medications they use for heart rate. There are a few of them, so usually that's up to the individual clinicians, which ones they prefer. There are a list of them on the POTS UK website. In terms of mental health, yeah, mindfulness is quite good. I think taking time out of your day is good as well. Some exercises, people might do Yoga, Pilates is quite good because you're on a more flat, floor based, and you're strengthening a lot of your core. Because if you think POTS is a lot of related to being in the upright position, actually if you do activity that's more floor based then that's quite good.

And any of those types of relaxation, anti-stress things are always positive. And I think I want to pick up one of the points that Jasmeet made around the importance of recognising what psychologists can do. And I think what I wanted to add to that is that there's a difference between psychologists and a psychiatrist. So a psychiatrist often looks at the bigger mental health condition to medicate them. So that might be medicating for conditions like ADHD, some things like schizophrenias... Not [inaudible 00:47:02] with schizophrenia, but psychiatry is very specifically more sort of medication focused, whereas psychology is a lot more around talking therapies.

Chantal Boyle:

Yeah. So I mean psychology, it's a little bit like... We all probably should have some experience with a psychologist, because it shows you how to deal with life, doesn't it? It's like learning to swim in a sense. It's a skill that's going to literally benefit you. Whereas I guess taking medication, and some people do need medication, there's something quite different and you might only take that for a short while. Whilst the psychology, I like Jasmeet, how you were saying how you are are really at one with yourself now, and you recognise things in yourself and your life that are really positive. These things would never have been even looked at or considered prior to you developing POTS. So I really like that way of health, health nourishment and management.

You are listening to the Sunflower Conversations with Chantal. To find out more about the topics discussed in this podcast, details are in the show notes.

We've had some questions through from the Sunflower community, so I'm going to go ahead and ask them now. And so question number one has come from somebody who has got POTS and their question is, where do I go from here?

Helen Eftekhari:

I think people with POTS need really good support. There are very few healthcare services across the nation, and I think the best source of support is POTS UK charity. Great resources, medically bonafide, and they've had really good vetting at the charity. They've also got online support groups. I think Jasmeet knows a little bit more about those.

Jasmeet Kaur:

So the charity runs support groups and the dates are published on the website and they are targeted at different topics. So for example, if you've just got your diagnosis or you are going back to work or at university, your parents or if you're male with POTS. So the focus of each session is different. They're great. It's just a way to come to talk, to get hints and tips. Nobody who attends is a medical professional, so the advice is kind of just from people with lived experience, but it's great. It's great to just be with your own people and we have a chat and there's no compulsion about, you know, you need to get dressed up... I attend in my nightgown, lying down in my bed with my hot water bottle. Many other people do. Some people attend from their living room, their dining table. It's just accessible and it's open to everybody.

Chantal Boyle:

That's really important, isn't it? To be able to bring your whole self, your whole self is in that moment to be able to come and that not to be a barrier. So we'll put the website details for POTS in the show notes so that people can find them. The next question is, will I ever get better? Helen.

Helen Eftekhari:

That's really, really difficult to know. There are different types of POTS. There's some that you recognise that probably have long-term, lifelong impacts, and there are some types, probably typically the ones that come from viral illnesses, that often if you apply a lot of the lifestyle changes and get the support, there is some evidence that that can get better. So the best thing is to have probably have a chat with your clinician about the type of POTS. Either one, I think if there's an acceptance that these are long-term conditions, whether you're looking at a few years or more of a lifetime.

Chantal Boyle:

Thank you. The next question we had, and Jasmeet did touch on it earlier on, is does food affect my POTS?

Helen Eftekhari:

It can do, in that... The first thing to say is that because it's the autonomic nervous system, it goes everywhere in the body. So therefore if your heart rate and blood pressure control system isn't functioning well then it's not unreasonable that something in your gut isn't functioning well. And we do see a lot of people with issues around gut as well.

The other thing that can be affected in terms of gut is that if you eat large, refined carbohydrate meals, so maybe like large portions of bread, pasta, rice, potatoes, those types of carbohydrates suck up fluid into the gut. You can, with a really, really large carbohydrate meal, sometimes suck up to about a liter of fluid into your gut. And a lot of the lifestyle advice around POTS is around having really good hydration and fluid intake. So some people will feel really, really tired after meals, sometimes not even large meals. But my advice would be little and often and reduce the amount of refined carbohydrates, or expect to lie down after a carbohydrate rich meal, not feel very well for probably the evening and put your feet up.

Chantal Boyle:

That's really great advice, and super interesting. I hadn't realised about the amount of fluid that gets absorbed.

Helen Eftekhari:

Not always. In very large meals. If you think when you cook pasta, you start out with a tiny portion, you cook it for so long until you get it to the al dente or however you do it, so that it could be just how you like to eat it. If you kept on cooking pasta, it'd probably fill your whole pan by the time you've finished, and it's in some big mush. You think that's probably what's happening inside your tummy.

Chantal Boyle:

My gosh, this is so educational. I had pasta last night. Okay, thank you. And our final question is are there any holistic treatments I can try?

Helen Eftekhari:

I think there's no evidenced holistic treatments, however, saying that, you can learn from other conditions and what benefits people. I think Jasmeet talked about the mind body connection. I believe, after having spent 25 years in clinical practice in cardiology, that mind body connections are really, really important, and a lot of my colleagues do as well. So those types of treatments, I think, are great.

There are no specific evidence around other things like acupuncture, maybe I'm thinking this person's thinking around those types of complimentary therapies or medicines that we would talk. That's always open for discussion, but there isn't anything evidenced around it. So I think most things we've talked about today that I would point people towards.

Chantal Boyle:

That's amazing. Thank you so much for your time, and Jasmeet for sharing with us your very open and honest journey that you've been on, and I can't wait to publish this to the Sunflower community and beyond. So businesses use them as well, it will help them to support their employees and all colleagues, family members. So thanks so very, very much for your time, both of you, today.

Jasmeet Kaur:

Thank you for having us.

Helen Eftekhari:

Thank you. I would just like to say, Chantal, if there are businesses out there, that really people with POTS have a huge amount of contribution to make to society and economics and functioning. And I think with very reasonable adjustments at work and an understanding that sometimes a small flu bug, which one of us might go into work and just say, "Oh, it's a little bit of a runny nose, I'm okay," and then it sends somebody with POTS off sick for a day or two, to have some appreciation and understanding of that and make adjustments as you would with anybody else.

Chantal Boyle:

If you are interested in any of the advice discussed in this podcast please follow up with GP or healthcare practitioner.

Speaker 1:

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