

Functional Neurological Disorder and Fibromyalgia with Gabrielle Hine

Speaker Key:

VO Voiceover

CB Chantal Boyle

GH Gabrielle Hine

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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. My name is Chantal, and I have the pleasure of being joined by Gabrielle Hine. Gabrielle has functional neurological disorder, which is sometimes known as FND, it's an acronym for the disorder, and fibromyalgia. So Gabrielle, or Gabby, is joining us to explain what the conditions are, some of the barriers she faces and how the sunflower supports her. So, firstly, welcome, Gabby. How are you today?

GH

I'm good, thank you, Chantal. How are you?

CB

I'm all right. I'm all right. So, firstly, could you please explain what is functional neurological disorder and how does it affect you?

00:00:58

GH

So, functional neurological disorder, as you explained, stands for... Sorry, FND stands for functional neurological disorder. And it is a problem with the brain and the nervous system and how the messages are sent and received in the body. And it's an umbrella term for lots of different symptoms. So, some people may have paralysis, some people may have non-epileptic seizures, they may have trouble with motor skills.

So, it's a wide-ranging term for lots of different symptoms, but predominantly to do with the brain and how the nervous system interacts with the body, really. So, it's a bit like if you had a letter and you addressed the letter perfectly, and then the letter, for some reason, ended up in a different household.

So, yes, that's the way I look at it. Some other people look at it in terms of apps on your phone, so when your phone doesn't work, but you know that your phone is working, but say an app doesn't want to install [?], that's another way of looking at it.

CB

I do like an analogy. Thank you for doing that, because that does actually help you picture and understand a little bit more when you think about the nervous system. And, yes, you can totally see like an app. It's not functioning as it should, but it is there on your screen.

GH

Yes, exactly. Exactly. And that's kind of how I view FND really.

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Everything, quote, unquote, looks okay, but for some or other reason, the messaging isn't getting through. And so, how it affects me personally, I get facial paralysis. So my eyes might close and my speech goes. And I also get kind of like a facial droop as well, and my speech can go completely, so I'm unable to talk. So, if that happens during our podcast, don't worry, it's just an episode.

CB

Okay. And how should I respond to that, if that happened? What do you want me to do?

GH

So, I tend to, with my friends and family, just do a thumbs up or a thumbs down as to whether I can continue what we're doing. So, thumbs down might be, I've had enough for today and I need to just have a lie down. And up is, I just need to take a few minutes, and then I'm okay.

My hands also claw. That's another symptom I have. It's called dystonia. That's the doctor's term for it. So, yes. For me, that happened... My first episode was July of 2020. And then I've had it since then, basically. But it's progressed from one eye being an issue to the whole face being a problem.

CB

So, both of your eyes will just close?

GH

Yes.

CB

You cannot open them?

GH

No, I'm basically blind. The mechanism just doesn't work. The eyelids won't open.

00:04:11

CB

And that can happen when you're wandering around or just relaxing at home.

GH

Yes, exactly. For me personally, there's no kind of tell or warning sign. It just happens. It's not like I get a headache before or there's some symptoms. People get a bit more of a warning, but mine would just happen. And it could be, like you say, when I'm completely relaxed, in my own home, or out and about in the world, which is, yes, a weird thing to happen.

CB

I would imagine it's quite anxiety inducing.

GH

Yes, yes, it definitely has been. When it first started, I was very anxious and I was quite housebound. I didn't want to see people. And before I got my diagnosis, it was kind of like, oh, what's going on? And I went through for... The doctor thought it was rare migraines and things like that. And then, because I didn't respond to the treatment, then they were like, no, this is FND.

And so, yes, it's been a whole rollercoaster ride of experience with FND, and then with the fibromyalgia as well. I know those two can sit in parallel, can't they, in terms of the condition.

CB

And they're both neurological conditions, aren't they?

GH

Yes. I think the fibromyalgia is more than the nervous system and connected to your brain as well.

00:05:46

CB

Yes. So, talk us through fibromyalgia.

GH

So, fibromyalgia is a condition where widespread pain is a factor. And you can also get muscle stiffness and your legs not working and things like that, as well as mental processing problems. So they call it fibro fog. [Overtalking] I call it that. So, I don't know if you've heard of that.

CB

Okay. I don't think I have heard of that term. I have heard of brain fog. I guess it's the same thing.

GH

Yes. It's basically the same thing, yes. So, sometimes, for me, I will try and find a word. I'm quite a visual person, so I can see what the item is in my brain, but I can't give the idea of what it is. So it might be I want the word for Hoover, but it's giraffe or something like that. It's very random. And it can make communication actually... Especially, I would say, the FND and the fibromyalgia for me personally seem to be linked. And so, it can make communication kind of a problem.

But I think now that I'm kind of four years into the situation of having both those diagnoses, actually, I think I deal with it a lot more with humour now, and it used to upset me a lot more, whereas now I'm just like, oh, well, it's just... For me as well, my face will completely turn down as well with the FND. So I'm just like, oh, that's my sad sad clown face, those kind of funny [?] moments you need sometimes to get through the difficult times.

00:07:32

CB

Yes, because they are invisible conditions, for sure. Nobody would know when they saw you.

GH

Yes, exactly. No.

CB

Right. That's interesting, that with the diagnosis and time, acceptance has also had to play a part. Do you feel that your symptoms have lessened a bit with the acceptance in how you deal with your health and processing as well?

GH

I think, yes, the symptoms haven't lessened, but I think the acceptance has helped. It wasn't until October of 2022 when I went into a rehabilitation, the Rosa Burden Centre. I went there for a couple of weeks, which was really good, and I think that I met other people with FND and that gave me a real sense of, okay, this is a condition. I'm not on my own. I think it's very easy with situations to feel very kind of isolated. And so, the symptoms haven't got better, but my viewpoint and reframing of the situation has improved, which is a positive.

CB

Yes, that is a positive. And it's really interesting to learn and be positive for other people to know that there are rehabilitation centres that can help with the understanding of what's happening, and also not feeling so lonely and isolated.

One of my questions is, can you describe some of the main challenges and barriers that you experience? And I would imagine that isolation was probably one of them that you may have shared with us. Can you expand a bit more?

GH

Yes. I think that's kind of my biggest challenge, I think, because basically, I was working from home when my first episode happened. I was working from home when everyone was working from home.

00:09:20

And I woke up one day and I couldn't see out of my left eye. And that was my first symptom. And, yes, life has really changed for me. And we'll go into that with the other questions that you've asked. But, yes, the barriers that I have I think are that every day, I don't know how my symptoms are going to be. There's no predictability. I can't say that at ten o'clock I'll be able to see to make a cup of tea during a day.

It's having to live life in a way that is really going with the flow, rather than being able to predict and say, yes, I can do this at this time, or whatever. And I'm lucky that I've got friends and family that understand that if I am not able to see them, or they pick me up and I go for a coffee and then I've got an episode, that they're understanding. And I think in these situations, you realise who the people that are in your corner are, really.

CB

Yes. Have you had to do a lot of educating, then, to those people around you?

GH

Yes, I have. And I've had people kind of think that because my speech goes, or sometimes it can be a bit slurred as well, people can be like, oh, have you had a

few, or something like that. Have you been drinking? No, no, it's just a neurological condition. I've had people not understand what's going on or look at me funny, because, quote, unquote, I look normal.

When it happens, I can see in their brain they're trying to work out what's going on. But then also, there's almost this, I want to use the word stigma, but I don't know if it's as strong as that, but there's almost this kind of, yes, maybe stigma or scaredness that people have of something that they don't understand, or something that that they haven't seen before.

00:11:24

Do you know what I mean? And so, when I have a face drop or when I've got someone guiding me along, or I've got my walking stick or whatever, I think it's like, well, she's not in the wheelchair, so what's the issue, type thing. I've had someone say to me before, oh, it's a good job you don't have children, because of your condition. It's like, well, lots of people who are disabled have children. Lots of people in life have children. So, I don't [overtalking].

CB

The statistic is one in six people in the UK have a disability. So I'm pretty confident that a lot of them are parents.

GH

Yes, exactly. Exactly. And just because I'm not currently doesn't mean I won't be in the future.

CB

Yes, it's such a sweeping judgement or statement to make.

GH

Yes, absolutely. Absolutely. And I think I've come across barriers I didn't even know were a thing until entered this kind of way of living. People just live on autopilot. We live on autopilot all the time, don't we, as human beings. Sometimes we don't even see the problem. So I think it's an everyday barrier, I think, also because there's a [unclear] time where I, quote unquote, look like a normal person.

00:12:58

So when it happens, people worry if they have to call an ambulance or anything like that. And it's almost like, oh, well, it's okay, you don't have to do that. It's like, well, no, I just have to sit somewhere quietly, and it will right itself at some point.

CB

On average, how long does it take for your facial paralysis to...?

GH

Sometimes it's been four or five hours. Sometimes it's been a little bit less. It tends to be less, but then what's interesting, and no neurologist or doctor has been able to tell me this, because I have the symptoms every day, they happen unpredictably in terms of how long they are, they can't tell me how long an episode would be. So I might have 45 face drops throughout the day. But no one's been able to say, oh, well, that's 45 episodes, or that's one episode. Do you know what I mean?

CB

I see.

GH

And it's interesting because I suppose, ultimately, it's however you perceive it, really. I don't know.

CB

Yes. And are you able to work? Do you have a job?

GH

No, I'm unfortunately not able to work, which is something I struggle with. I gave up my job a couple of years ago, and. And it's predominantly because the symptoms are so debilitating and it affects my sight, they affect my speech, they affect all these things. And it's just not something that is possible in a workplace. I can't say to an employer, oh, I can definitely work for eight hours a day, when I may not be able to see or type.

00:15:02

CB

Yes. And would you say that the FND is actually what causes you the most barriers, as opposed to the chronic pain that you experience with the fibromyalgia?

GH

Yes. Yes, 100%. I do. I do. Some people with fibromyalgia, their symptoms may be worse than mine or whatever, but it's so individual. Health is so individual, isn't it, that I personally feel that FND has made not being able to work and my everyday life more of a challenge.

And I think for some people, in terms of FND, that can be via certain triggers in life that have happened, or life events. Some people have had no life events or

triggers that have attributed to their FND, whereas I have. I was born premature, so I was 24 weeks. I had a lot of health conditions, brain bleeds and collapsed lungs, and lots of different things.

CB

You really have had a trauma.

GH

Yes. Yes.

CB

And that's what's been the catalyst for this.

GH

I think so. And friends who I know who are paediatricians and things have said, you had to fight very hard to survive. And you've done that, but then your body has been quite vocal in later life about that, if you know what I mean.

00:16:42

CB

Yes. There's no magic pill, is there?

GH

No. Everyone, obviously, does things differently. For me, I've done a lot of mindfulness. Some people hate the word mindfulness or hate that, but I've really been aware of relaxing my body and my nervous system. And I think a lot of people with FND or those kinds of conditions will be aware of fight, flight, freeze and form.

And I think FND for me personally, but I think others as well, is our body's response to the fight, flight or freeze, sorry. And so, for me, when my symptoms happen, my body just shuts down with my eyes and my speech. That's that freeze technique. And so, I try and use my senses. So, some nice candles or hand gels.

It's not going to make my situation... It's not a magic wand. It's not going to change my episodes, but it might change how I'm feeling during that time. Through having FND and learning more about the different kind of fight-flight responses, that's the word, I think I've understood a lot more about myself. And I've also been able to work through those barriers that I even had with myself in terms of putting my needs and my own requirements first. And that's been a whole new journey.

CB

It's a whole journey, yes. That's hard work to constantly change your approach, your natural human responses, to try and switch that around. That's been a lot of work on yourself.

GH

Absolutely. It's just given me a different way of doing things and I feel a lot stronger for doing it in myself mentally, being able to see what I need to do, rather than what someone may need from me in a situation. I don't even like people singing Happy Birthday to me, being in the spotlight. Any kind of spotlight, I just want to hide.

00:19:15

So I've had to really work on that myself. I constantly, even when I'm with my family and stuff, in my head, I have to constantly tell myself that I'm safe and I'm okay. And it's that inner kind of work and working through all those things to just calm the body, because it's that strange thing, I think, Chantal, isn't it, between we are physical beings in our body, but sometimes we just don't connect to it at all.

And I think I hadn't really realised how much our bodies just go through in life in general, let alone when we're in these situations.

CB

So, let me ask you about the Sunflower. Yes. Why do you wear the Sunflower?

GH

I wear it because I feel it gives people an idea, okay, there's something going on there. And a lot of people have asked me, oh, is this your work lanyard, if I'm out and about during a lunchtime with a friend or whatever. And I explain to them, no, it shows that I've got a hidden disability.

And it's great, actually, being able to go into places, have it around my neck and the information on the card, and to show it to someone and just say, okay, this is the situation, I may need some more time, I deal with a hidden disability. It just gives me peace of mind that I never had before discovering it existed.

00:20:51

And it gives me a confidence in being able to just be and exist and not have to explain, because I don't know your experience with this, but it's exhausting having to explain to people a situation.

CB

Yes, everybody interacts with the Sunflower in different ways. So, how do you interact with it? Do you wear it every day? Do you wear it as specific places, or

how do you choose to wear it?

GH

I wear in a public place, so if I'm out and about, I wear it. And it's been great, actually. I went recently with my cousin to the Netherlands, and I wore it to the airport, and I wore it, and everyone knew about it. And the fact that there are airports now, like Bristol Airport, I'll just do a shameless plug to Bristol Airport...

CB

Yes, yes, go Bristol.

GH

Yes. They have a special Sunflower walkway now. So, everyone at the airports are aware of it. And even when I got to the other end, Amsterdam, they knew about the lanyard. The museum that we went to knew about the lanyard. It's amazing that there is this level of awareness and understanding, and it's just great, isn't it? It just gives you that level of peace of mind that I certainly didn't have before I realised it was an option.

It's just like a breath of fresh air, really, just being able to feel, quote, unquote, normal, but knowing that you've got a safety net as well, know what I mean?

CB

It's really interesting, yes. And it's really lovely to hear and describe how and why you wear it and how it makes you feel, especially given the fact that you said you don't like to be the centre of attention, because often some of the inquiries or comments that we see from people is, oh, is it going to make me stand out? Is it going to make me a target? Is it going to really highlight?

00:23:00 So for you, describing what your natural personality is like, but actually, it gives you the peace of mind and it feels like a breath of fresh air for you. I think that would be really helpful for other people to decide whether or not it would be of benefit for them to wear.

GH

Absolutely. Absolutely. And I think it is purely a choice thing, isn't it? And I think it's really nice when sometimes I'm wearing the Sunflower in the street, and then I see someone else with a lanyard, and it's like, oh, that makes sense. And I know what that means and they know that means. And it's a community as well as a symbol, really, isn't it?

CB

It is. It is a community. Absolutely. Do you mind if I ask you to share what icons you've chosen for the back of your card?

GH

Yes. Yes. So, I chose the one about queuing. It's literally across my room right now. I can see it. And then I've chosen... The standing one is the one about standing, not being able to stand. I can [unclear]. And [unclear]. And this other one about just needing a bit more time maybe. Yes, yes, just because I thought they fitted best with my [overtalking].

00:24:26

CB

Yes. A bit more time to process information, communication, or just generally. Yes.

GH

Yes, absolutely. And it's really good because even I went to a library the other day with a friend, our local library, and they've got wristbands now. And it's really nice and reassuring to see that you can go to most public places now.

Even big supermarkets and people are aware. And it just gives you that level of reassurance that you can go out and not have to... I just feel like in life, you have to kind of... Or you're not obliged to, but you're kind of given, you're having to explain. I find shops quite overwhelming, just sensory overload, anyway.

And I think sometimes if I hadn't had my lanyard, for whatever reason, if I've forgotten it at home or whatever, if I don't have it, I always kick myself because I'm just like, if I had that, then people would know. I think a lot of the big retailers now, food shop retailers, you can get it free, can't you?

And it's just great to be able to let people know that it's there and a really good resource, because I think the fact that it's also understood internationally gives people, hopefully, that reassurance that they can try new things, like my time when I went to Netherlands with my cousin was the first time I'd been abroad since becoming unwell. And that was a complete eye-opening experience, because I was wearing it and, oh, this is great, and people knew about it.

00:26:18

CB

So, what would you like most for people to know about FND and fibromyalgia? When they finish listening to this podcast, they maybe didn't know very much about it or anything before, what would you like them just to remember?

GH

I think, to remember that, it sounds really silly, but that even though these things are neurological conditions and a brain condition, people will say, oh, it's all in

your head. Or I've had a lot of situations where people have said, oh, they've been not believed or been kind of belittled in a way, or not understood about the conditions that we're talking about.

And I think that it is real. It is recognised more now. The medical community and people like yourself and me are really trying to advocate for hidden disabilities. And I think we are slowly but surely changing that viewpoint, which is amazing. And I think just education is the biggest thing, I think, with any kind of condition, and acceptance and community.

And I think there are a lot of... You've had FND Hope on here before, who are amazing and do incredible work. And there are a lot of support networks and online communities out there that I would recommend and have helped me get through and understand and learn from living with FND.

And so, what I would like people to know is you're not alone, and there are people out there who can help and have experience of it. Yes.

CB

That's great. So, FND Hope then, we can include that in the show notes. There is [unclear], guys, if you want to listen to that. It was excellent. It was with the professor and Dawn. So, do have a listen to that, because there's some great tips in there and advice. So we'll include that in the show notes.

00:28:24

And do you have an organisation, charity that you would recommend for people who have got fibromyalgia too?

GH

There's Fibromyalgia UK, which are very good, but actually, I did Google this morning. I was just looking at fibromyalgia as a thing. And apart from that, there doesn't seem to be that many organisations out there. But I think the biggest ways I found through community has been social media. It's been Facebook, Facebook groups about fibromyalgia FND. Yes, that's been the biggest thing.

CB

That's great, because I think what I've learned from doing this role and being the host, getting the opportunity to speak to so many wonderful people such as yourself, is that once somebody becomes diagnosed, they become an expert in that condition because they do so much research.

GH

Yes, absolutely. And there's also FND Friends, FND Dimensions and FND Action and FND Wellbeing as well. There's plenty of places out there that just give you that knowledge and that education and people to talk to as well. It's not just you.

You're not an island, because it really does feel like that when you're told about these conditions.

CB

That's a really nice sentence to end on. It's not just you. You're not an island.

GH

Yes.

00:30:02

CB

Thanks so much, Gabby. I really, really appreciate your time, and for the analogies as well for understanding, get a better understanding. We've spoken predominantly more about FND today, but you have given us an insight into fibromyalgia as well. So, thank you so much.

GH

Absolutely. That's great. Thank you, Chantal.

VO

If you'd like to share your Sunflower story or conversation, please email conversations@hiddendisabilitiesstore.com. Find out more about us or listen to this recording again by checking out our insights page at hiddendisabilitiesstore.com. You can also find us on Facebook, Instagram, Twitter, YouTube and LinkedIn. Please help, have patience and show kindness to others, and join us again soon. Making the invisible visible with the Hidden Disabilities Sunflower.

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