

Functional Neurological Disorder with Dr Chris Symeon and Dawn Golder

Speaker 1:

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

Chantal Boyle:

Welcome to The Sunflower Conversations with Chantal. Joining me today is Dr. Chris Symeon, a consultant neuropsychiatrist at St. George's University Hospital NHS Foundation Trust and the clinical lead for FND Rehabilitation Program. He is passionate about developing services to allow patients with FND to access high quality treatment in a timely way.

Also with us today is Dawn Golder, who is a national advocate of FND Hope UK and has lived experience of FND. FND Hope is the first nonprofit organisation specifically for those diagnosed with functional neurological disorder and related illnesses. Hello to you both. Thank you both for joining me. Chris, what is functional neurological disorder, and how might it affect someone?

Dr Chris Symeon:

So, FND or functional neurological disorder is a really common neurological condition. It happens because of a problem with brain signaling. So, it's involving brain networks rather than specific anatomical damage and it can affect any part of the nervous system. So, no two patients will experience the same type of symptoms. It can affect anywhere in the body essentially.

But people tend to have either sensory changes, so feeling different sensations on the skin, so numbness or increased sensation. Or, motor changes. So, weakness or tremor. Sometimes people have things like seizures, so functional seizures. So, I think it's quite difficult sometimes for people to understand that, because it's got such a wide vast variety of different types of symptoms. But sometimes we say it's a bit like the train tracks, really. So, you must have heard of signal problems on train tracks causing disruption. So, it's very similar to that whereby the train tracks themselves are completely intact, but there's a signaling problem, communication problem. So, that generally is how we think about FND.

Chantal Boyle:

That's a good analogy to explain that. So, is it a relatively new illness?

Dr Chris Symeon:

So, it's very much not a new illness but the way that we speak about it is very new. So, it's been a problem within the medical community really, that we use different terminology to talk about the same thing. So, it's been called many, many different things over the years from conversion to dissociation to medically unexplained symptoms to non-epileptic seizures.

So, it's quite problematic because many of those things describe what it isn't, you're saying it isn't X. But actually, what we're trying to do now is say it's functional neurological disorder. So, it's a problem with the function of the nervous system. So, it's very much not new but the way that we talk about it is. It's very, very common as well. So, up to 20% of patients attending neurology outpatient clinics are there for FND. I think the medical community is only now just catching up with how we define it and I think that's probably why we're a bit behind in terms of the medical progress that we've made so far.

Chantal Boyle:

That's really interesting. So, I had a little read up about it, and fibromyalgia, ME, Parkinson's, how do doctors and neurologists determine the diagnosis? Does it come under the umbrella of FND? Because you just mentioned about non-epileptic seizures, so would that now be diagnosed as, "You have FND."?

Dr Chris Symeon:

So, functional seizures are under the umbrella of FND. Yes. So, as I said before, because FND can affect any part of the nervous system, it can be quite challenging to get the diagnosis. Many patients have been around to a number of different specialists and clinicians, even just to have a diagnosis let alone get the treatment they need. To see the right professional is the key part of the diagnostic pathway. So, usually the person to diagnose would be a neurologist and they would start with a physical examination. So, they would assess the neurological function, motor function, sensory function, and they might refer on for some tests. So, they might ask for a scan or some blood tests to rule in or rule out different differentials that they've got.

They might also ask for a consult from someone else like a psychiatrist or a different therapist for instance. So, this is part of the whole pathway of getting a good diagnosis early on. I think a problem that we hear a lot about is that often people are told there's nothing identifiable, there's nothing there on the scan or a blood test, and then it's like, "Well, goodbye." But then the person's left with quite disabling symptoms, and that non-answer is a real problem. So, I think we're getting better as a medical community at actually positively diagnosing FND. And there are a number of things that you can tell from even an examination quite early on that indicate FND in the neurological examination. So, different types of movements, the way that they respond to things like distraction are all telling signs that it might be FND.

Chantal Boyle:

You are obviously an expert but is getting an accurate diagnosis, is it a postcode lottery?

Dr Chris Symeon:

I think getting a diagnosis is a postcode lottery but less so than treatment. I think realistically, if you're seeing a GP, a GP should then refer you on to a neurologist and that neurologist should be able to do those things that I just mentioned and then diagnose FND.

You might then have a problem with accessing treatment however, and that seems to be a bigger postcode lottery because the treatment centers are very few and far between nationally. We're trying to support clinicians, particularly GPs and neurologists, in picking up and screening for FND early on in that pathway, to streamline that process.

Chantal Boyle:

And we're obviously now on the tail end of the pandemic, but COVID is still ever present. Is there any evidence that COVID caused anyone to develop FND? Are they linked in any way?

Dr Chris Symeon:

So, when we talk about what causes FND, we think about triggers. So, it's often the case that there might have been something around the onset of FND that could have been physical, like an illness, like COVID, or it could have been psychological, so significant psychological stress for instance. Often, that's on the top of lots of other things that might predispose someone to having FND. So, they might have had other neurological conditions, they might have a family member with a neurological condition. They might have difficult social circumstances.

So, all of these things on the back, plus a new trigger like COVID might precipitate the onset of FND, but I think it would be a stretch to say that COVID causes FND. And actually, there's been some anecdotal evidence that some people find that their functional symptoms are improving actually, when they've been infected by COVID acutely. So, I think the jury's still out on exactly how we see the link between COVID and FND. I think at the moment, we should just think of it as a potential trigger for the onset in the same way that another physical illness might be a trigger.

Chantal Boyle:

Thank you. So, in the UK, how many people have FND and has the diagnosis increased recently in light of what Chris has just been saying, Dawn?

Dawn Golder:

So, the difficulty we've got is that it's very difficult to try and calculate exactly how many, because we don't have the data to almost say exactly how many people, because they are almost coded very differently depending on where you are in the UK. So, at the moment we estimate there to be between 50 and 100,000 people living with FND, and I think I'm right in saying, Chris, that I think there's about 8,000 new cases per year of people being diagnosed with FND. And I think we are starting to see an increase in that. But why that happens, we can't really say. It could be anything to do with COVID. It could be because we're getting better at diagnosing people. But we are seeing an increase, but as a guess, it's an estimate.

Chantal Boyle:

And have you noticed an increase in people seeking support from FND Hope?

Dawn Golder:

Yeah, we have and I think a lot of that is, as Chris already spoke about this postcode lottery of getting treatment, and I think because the introduction of the new ICSs, so they're obviously taking over the CCGs now.

Chantal Boyle:

Oh, sorry, Dawn, what is that, those acronyms?

Dawn Golder:

ICSs are the Information Commission Services. So, your CCGs used to be how you budgeted for treatment. So, the CCGs are now no longer in place. So, ICSs are now trying to bring health and social care into one bucket, let's say. So, because the introduction of those, they will only now look at the areas that they are ... What's the word I'm looking for? FND brain. So, they're only looking at the area that they are assigned to, let's put it that way.

So, it's now going to be very difficult for people to try and access treatment outside of their catchment areas. While as before you used to be able to be referred outside of your CCG area. So, it's now going to be very difficult for them to get that access of treatment. So, the postcode lottery is now going to become bigger.

So, because of that, we are now seeing a lot more people saying, "I've been diagnosed with FND but I can't get access to treatment." And that's because they just don't have the ability to set up an FND service. I think there's a lot of people that want to do that, but a lot of that is down to funding. A lot of that is down to training. And I guess it's just hopefully us trying to work with those people to say, "We now need this kind of access because there are a lot more people being diagnosed with FND."

Chantal Boyle:

So, FND Hope is a spokesperson for people living with FND to lobby?

Dawn Golder:

Yes, we are. Yeah. So, we've worked with the Neurological Alliance and also the National Neuro Advisory Group, to create what we class as a optimal FND care pathway. So, if you think of any other neurological condition there would be a pathway. So, for instance a stroke, you would be assigned a pathway that you would go down.

For FND, we don't have that, not everywhere. So, we've created this optimal FND pathway and now what we want to do is to try and work with ICSs to implement this pathway. So yes, we will be lobbying for that. We will be taking all of that to parliament, to Westminster, to say, "We now need more funding, we need these access to treatment."

Chantal Boyle:

Can you tell us how FND affects you?

Dawn Golder:

So, it's morphed and I think a lot of people will say that it morphs. So, when I was originally diagnosed back in 2015, so I had labyrinthitis. Within about a week, I started having left-sided weakness and then I started having paralysis left side, and I was originally diagnosed as having a stroke. And then I had another stroke-like episode, another stroke-like episodes. So, they started thinking, "Oh, maybe you're not having strokes, maybe there's something else going on." So, then there was talks of hemiplegic migraines, atypical migraines. And then I was finally diagnosed as having FND in 2015. I was told, "12 months, you'll be better. Labyrinthitis will disappear, so you'll be fine."

So, fast forward with 12 months. So 2016, I was pretty much wheelchair bound. I had a real twist in my body, so the bottom part of my body was twisted. I was having seizures, tremors, I sometimes had difficulty talking. So, I then asked to be seen by an FND specialist in London. They did an assessment and I was very lucky that I was then referred to inpatient treatment, which I think was in 2017, 2018. And I spent 12 weeks relearning how to walk and I'm going to put in inverted commas, "normally". I stopped having seizures and I felt fantastic. It was amazing.

And then, three months after that, I had another bout of labyrinthitis and my symptoms returned. So, for the last four years I've been almost battling new symptoms. So, I still have the occasional functional seizure, but I now have quite strong spasms, where I guess the trunk of my body really spasms that much that it can take my breath away. My gait is very, very weird. When I talk about gait, I'm talking my legs will just walk however they want to walk. Whether that's turned in, whether that's turned out, whether that's twisting to one side or the other. I have issues with remembering words. So, communicating can sometimes be very difficult. Fatigue, pain. So, all of those different types of symptoms, I struggle with now. But as you said, it does morph.

Chantal Boyle:

As well as being incredibly debilitating and painful, you must be continually assessing yourself. Like, "How do I feel now and what's happening?" Or, "This is a new symptom." That must be so tiring and also worrying.

Dawn Golder:

Yeah, very. So, I never know from one day to another how I'm going to wake up, because that's when I normally have the symptoms upon awakening. I now suffer from, I'm going to say, extreme anxiety. So, I actually don't go out on my own because of the fear of having a seizure where I feel vulnerable, or a spasm attack, or any other symptom, I guess. So, I have now become quite isolated, very alone. So, obviously that then has a negative impact on your mental wellbeing.

So, all of that, I guess, social aspect of your life suddenly then becomes very, very minimal and it does have a knock-on effect to your mental wellbeing. There are days where I feel very, very down, very, very depressed. There are other days where I think, "No, come on, you can do this." But it is very, very tiring. You do also worry about if you do decide to go out on a day out with family, what impact is that going to have on the next day or two days after that? Because you end up going through this boom and bust cycle where you think, "Having a great day, I'm just going to go and do everything I want to do." And then two, three days later it could suddenly hit you with lots of symptoms. So, it's a constant thinking about, "How do I plan my day-to-day so that I don't have that knock-on effect?"

Chantal Boyle:

And prior to you being an advocate for FND Hope, were you working before all your symptoms started?

Dawn Golder:

Yeah, I was, I was working full-time. I would say I was very much a workaholic. So, loved my job. I would probably work eight, nine hours a day, traveled an hour there and an hour back, and then I'd come home and I'd do dinner and go out socializing. Yeah, I was very much that life and soul of everything, really. But I would definitely say that I'm not necessarily that person now. I'm a different person and I think I do like the person sometimes that I've become because I've become more, I guess family orientated rather than work orientated. But it's sad that this is how I've turned out.

Chantal Boyle:

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Once you started having the treatments, would you say that your FND has improved? Are you getting less of those mini-stroke type episodes?

Dawn Golder:

So, I'd definitely say the treatment helped. It absolutely is the best thing that ever happened to me, having that treatment. I guess, I'm just an unfortunate person that symptoms have come back. They're probably not to the same extreme as they were previously. So, that's always a positive.

But I'm hoping to be able to get additional treatment, so hopefully these little bits of symptoms that I get now will be able to be supported and helped. But yes, treatment is the best thing. I think if you can get that treatment quickly and you have a great team beside you that understands FND and works with you, you can make some amazing progress.

Chantal Boyle:

Good. So, I guess that brings us on to treatment. What types of treatment are there? What exists, and how can people get access to them? And picking up on what you said, I'm assuming it's a physical and psychological treatments, Chris?

Dr Chris Symeon:

Yeah, definitely. So, there's a lot of different types of treatment that are available, but it does very much depend on what the individual has. So, for instance, if someone has primarily motor symptoms like weakness or tremors, it might be that they can just have a physio, FND-informed physiotherapy, essentially.

For a lot of patients though, they usually will need what we call multidisciplinary, which is having lots of different professionals involved. So, it might be that there's a physio, an occupational therapist, speech and language therapist, psychologists and doctors, specialist nurses, a whole team of people. And I think it's really worth saying that I'm describing it as if you can just arrive at this MDT input, but actually, often people are waiting on waiting lists for years to access treatment and it really isn't acceptable really for that to happen, because it doesn't happen for any other neurological condition.

So, what we see is by the time people come in for rehabilitation, their symptoms are actually more severe. They've had losses, perhaps they've not been able to go to work, so they've lost their job. They've not been able to do the school run or they've had to get other people involved. So, it's really affected their quality of life and their family. And we have to help them to rebuild actually, their identity often as well, who they are, who they were. So, the first thing I would say is, what we're trying to do is fight that delay essentially and try and improve access. And that's again going back to what Dawn has mentioned about trying to lobby for there to be a pathway that allows people with FND to access treatment in a timely way.

But going back to the actual interventions, most patients who come through rehabilitation have a combination of those therapy inputs that I mentioned. The common thing, again as Dawn has mentioned, is that boom and bust cycle. We often see people who come in and they want to give it their all, they've waited two years on a waiting list, of course they want to give it their all. So, they come in and give it 110% but actually that leads to a downward trend with energy and function.

So, what we try and do is pace rehabilitation in a way that patients can continually improve. We set goals according to what they want, not what we want, and we involve all the disciplines whether it's initially indicated or obvious or not. So, even if someone doesn't present with psychological or psychiatric symptoms, it's really important to have a psychologist and psychiatrist involved, because just being unwell for that long will make you experience anxiety and depression, won't it? So, it's important to explore that and treat as well if there is any anxiety and depression as well.

I guess one more thing I wanted to mention about treatment is that with innovation how it is now, we're seeing and doing a lot more virtual work and there's a lot more remote access to therapy. So, it might be that if people who are listening to this can't access rehabilitation where they are, it might be that they can be referred to access remote rehabilitation and it might be that even if that's not what they need in the longer term, it might be a good stepping stone to small improvements before they get to the treatment they need. So, it's worth just flagging that virtual rehab can be really quite effective as well.

Chantal Boyle:

That's one thing that the pandemic has given us. It's that opening up how tech can support you at a home. Whereas before it was like, well, if you can't get into the surgery or you can't physically get there, then it's not happening. And we've all had to adjust how we approach everyday activities, haven't we? So, I guess that is one of the positive things to come out of that horrible period. And is accessing support that FND can help with that or is that not possible because of how you were describing these pots of funding for certain areas?

Dawn Golder:

So, it's very, very difficult for us to be able to try and fund somebody to go and get treatment. So, that's something that we unfortunately are not able to help with. However, because FND Hope have a great working relationship with different medical professionals across the UK, we have a sense of where they may be able to access that kind of help and support. So, we can almost tell them where to go depending on where they are within the UK.

We also have a find a provider tool on the website, so people can go onto the website, put in where they are within the UK and it should be able to come up with either NHS or private medical professionals that can help treat them. So, that's definitely something that we can help with.

But we also have online wellbeing and movement type classes they can access. So, things such as yoga, Pilates, mindfulness meditation, art. We also have peer support groups as well, so they can almost help support each other. But we're also trying to bring in almost like different classes to help with their wellbeing, which can also be really helpful. And we've just also started offering three week mindfulness for positive coaching courses, and that's in collaboration with a lady called Irene Garcia who works at the Rosa Burden Centre, and we've had some really positive feedback. So, mindfulness can be really helpful for people with FND to try and help ground them, to help with meditation. So, all of that can be really helpful for those. So, we've started to offer those. So, whilst we can't offer treatment as such, we've got some classes to help them in the meantime.

Chantal Boyle:

That's great. Well, at the end of this we'll take the website so that anyone who needs to can get access to the types of support that you've just mentioned.

This is the Sunflower Conversations and the purpose of this podcast is to raise awareness of non-visible disabilities and the Hidden Disability Sunflower is worn by people who have got invisible disability, who want to be met with a bit of patience, kindness, and understanding by others. Everything that you've just described, well most of what you've described, nobody would realize that you have this condition if they were to meet you or see you, but obviously you are living with some extreme symptoms which can be incredibly debilitating.

So, we spoke to the Sunflower wearers to ask if they had any questions, and I have to say it's been the biggest response when I've asked this out to the Sunflower community. So, I'm just going to put a couple of the questions to you both. So, Peter got in touch via Twitter and he wanted to know, "Does food have an impact on symptoms?"

Dawn Golder:

Not that I'm aware of, Chris.

Dr Chris Symeon:

So, I guess I'll start by saying, food and diet has an impact on health and therefore, naturally will affect your wellbeing, health and wellbeing. As we were saying before about the pacing and energy expenditure, the body doesn't like big waves, it likes predictable energy intake, it likes everything to be within certain levels. And I think the same goes for your diet. And generally, we would advise that someone has a nutritious, balanced, regular dietary intake, because if you get peaks and troughs of high glucose, low glucose, and things like that, it can really affect how your body functions, how you feel as well, how you are emotionally.

And I guess also within that, there are lots of vitamins and minerals which are important for good neurological function. So, we know things like magnesium, calcium, sodium, lots of vitamins like B12, vitamin D, they are relevant and essential for healthy neurological function. So yes, it's important to have a nutritious balanced intake and if you think that you might be deficient, it's worth getting assessed by a doctor.

Chantal Boyle:

Thank you. Our next question was from Carol via our Facebook page. Carol was diagnosed with NEAD, non-epileptic attack disorder four years ago and she would like to know, "Should she be checked regularly by a doctor?"

Dr Chris Symeon:

So, the first thing I'll say is, well, it is not clear whether you've had help or treatment. So, I guess getting checked regularly by a doctor, that's okay for follow-up so that you're not lost to the system. But actually it sounds like you need treatment, really. So, I think the first thing to say is, ask for treatment because often clinicians might not know that there is available treatment for this. And again, the terminology used, NEAD, suggests non-epileptic attack. I guess it might be that you go back and say, "Actually, I've got functional seizures and that I need treatment for that."

For functional seizures, usually it's one-to-one psychology input or group psychology input. So, actually there's really an emerging body of evidence to show that that's actually quite helpful and can help reduce the frequency and severity of seizures. So, the first thing I'd say is, get the treatment but don't stop seeing your doctor, because I think sometimes if you stop getting those checkups, you fall out the NHS system and it can be even harder to get back into the loop afterwards.

Chantal Boyle:

That's really good advice. So, thank you for that. We've got another query from Patricia via Facebook. She says, "Please help. I'm a 61-year-old female in a state with FND, unable to do anything. I have screaming headaches, fluid in my eyes, please help me."

Dr Chris Symeon:

So, it sounds really, really horrendous, actually. It sounds like it's quite traumatic what you're going through, and again I would say, just because you've been told that it's FND, it doesn't mean that you don't deserve care and treatment. So, just because the access to things like the MDT rehab I've mentioned, aren't easy, it doesn't mean that you don't deserve help, basically.

So, it sounds like you're in a bit of a crisis. And also there's this thing called diagnostic overshadowing whereby someone can have FND, yes, but actually if you've also got really bad headaches or new eye symptoms, doesn't mean that you can't have something else going on. It doesn't mean that everything is due to your FND. It's really important not to miss something else if there is another diagnosis going on. So, I would say, go back to your clinician and really recommend that it is worth a workup. Also, treatment of headaches is usually quite good. So, we've got lots of treatment hubs for headaches and migraines now, set up all across the country. So, it might be that there's things that could be done specifically for your migraines or headaches, to help you have a better quality of life, really.

Chantal Boyle:

Actually, it's really a good thing to highlight there, isn't there? Because FND is such an umbrella term for so many different effects that can happen to your body and your mind, that a lot of other things could then go undiagnosed. That's a good point to raise. And the last question here is from Trish via Instagram. "I have regular therapy and my pain specialist from a private clinic in Queen's Square London, but they have discharged me saying there's nothing more that they can do. My biggest question is, where do I go from here?"

Dr Chris Symeon:

So again, Trish, that sounds very difficult, because it's that sense of abandonment that lots of people have with FND, it's like, "Actually, the road has ended here, good luck." And it's kind of, "Where do I go from here?" And again, I'm not entirely clear about the diagnosis from what you've said so far, but I would say going back to that basics of, what exactly is the diagnosis that you are trying to treat here? Is it chronic pain? Is it FND? If it's FND, what type of FND? And support the process of trying to access the right therapy discipline from that.

So, I would maybe go back a bit and when you've had different types of inputs from different types of specialists, things can get a bit muddy medically. So, you get lots of these labels that you collect, lots of these medications you collect sometimes as well. People have 20 medications that they take daily and often, maybe not needed. So, it's worth just reviewing and revising what's happened so far. What's my current state of play? And what do I currently need treatment for?

Chantal Boyle:

I didn't ask this but is it more prevalent in men or women or is there not a distinction?

Dawn Golder:

It's more prevalent in women than it is men, by three to one.

Chantal Boyle:

Dawn, or either of you, is there any financial support for patients who can't work or need to take early retirement? Because it does sound like the most debilitating health condition at times.

Dawn Golder:

So, I think our recommendation would be for them to apply for PIP. So, Personal Independence Payment, or Employment and Support Allowance, or Universal Credit. Unfortunately, we don't, as in the charity, don't have anybody to help support that at the moment, but I know that's something they're looking into. However, I would suggest probably going to see their local Citizen Advice Bureau. They will be really, really helpful in trying to complete those forms. And I think there's a benefits calculator on the government website and also another charity called Turn2us, and they might be able to do that benefits calculator to understand what they're entitled to. So, I would definitely suggest they do that.

Chantal Boyle:

That's really useful, because I've heard that completing the forms, particularly I've heard about the PIP one, is really overwhelming. And if you're not feeling well anyway, it's very difficult to navigate around an overwhelming form, isn't it? And ultimately, if you don't have anything to finance your living expenses, then you're going to be in dire straits.

What do people need to consider regarding driving safely? As it's a lifeline to independence, but many people are worried about having to give it up. This question is also via some of the questions that we were asked to present to you guys.

Dr Chris Symeon:

So, I think it's worth dividing this really into two parts. One is people who experience functional seizures. So, the DVLA have quite clear guidelines on functional seizures, that people should be seizure free for three months before driving and you need to inform the DVLA if you're experiencing seizures. So, that's clearer. It's less so for other functional symptoms because they get lumped into chronic neurological conditions, and there's so much variation.

Realistically, the guidelines suggest that the symptoms should not be so severe that they impact on driving, but that leaves a lot of room for guesswork really, and interpretation. However, I would say it's always worth informing the DVLA because if for instance, something happens, you wouldn't want to be doing something illegal and invalidate your insurance or obviously you wouldn't want to cause an injury to yourself or someone else.

So, it's worth just flagging to them, "Look, I've got this neurological condition, it affects me like this, I manage it like that, and this is what I think I can do." It might be that they say, "Hold off driving until you've had treatment and then we can ask your doctor for information." So, I regularly get contacted by the DVLA for information from my patients to say, "What do you think about them driving, and what's their symptoms like?"

You might be asked to do a test, a retest or a reassessment in one of their specialist centers. But again, for the most part, if somebody has well controlled FND, generally the DVLA are quite lenient and do permit people to drive, but I would always suggest contacting them and being upfront. If you're not upfront and then they understand that you have got a condition, which you haven't said, I think they'll be less lenient afterwards.

Chantal Boyle:

It's about not only keeping yourself safe, it's keeping other people safe, isn't it?

Dr Chris Symeon:

Yeah. I think there's also something about blackouts and faint attacks, which obviously within FND can occur as well. And again, I think there's a bit of a gray area because sometimes faint attacks can be quite predictable for some people. They know when they're going to have one, they get warning signs, they can pull over. It only happens when they stand, for instance. Whereas for other people it might be completely different. So, I think just giving that information to the DVLA will help them to come out with an outcome.

Chantal Boyle:

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Dawn, you mentioned some support that FND Hope have organised virtual sessions, et cetera. So, we can put that in the notes. Can you just give us the name of the website for people that need to jot it down?

Dawn Golder:

Yep. So, it's fndhope.org.

Chantal Boyle:

Fantastic. And Chris, are there any other training or seminars that people can attend? Or Dawn, do you know of any other ones?

Dawn Golder:

Yeah. So, I know that FND Hope UK at the moment are creating an FND masterclass. So, one of the things that we've highlighted is that people are diagnosed, not really given a lot of information about their FND, and then they're almost given a website. So, we want to try and bridge that gap, I guess. So, the FND masterclass will be about educating people about what FND is, and they are co-producing this with medical professionals as well as service users. And we want to be able to run this on a monthly basis, so that those that are newly diagnosed or even those that even had FND and want to learn a bit more about it, will be able to attend those sessions every month.

So yeah, we are definitely doing that. And they're also looking to create some education modules that we want to get CPD accredited. And that's about trying to educate GPs, nurses, paramedics, medical professionals, allied health professionals, and we want to break those down into very small training chunks, so that they can look through these within their lunchtimes. So yeah, FND Hope UK are currently looking to do those, which hopefully will help.

Chantal Boyle:

Brilliant. And Chris, do you know of any training sessions that people can join?

Dr Chris Symeon:

So, those are the main ones that are up and coming. There are some NHS organisations which are offering open days and education sessions specifically for different things like functional seizures or functional cognitive disorders. But it's a bit hit and miss depending on where you are, and it's more likely to be available in a major center. So, major city, essentially.

Chantal Boyle:

And the main questions that were coming through are, "Where do I go from here?" So, may I ask what your top three suggestions might be?

Dr Chris Symeon:

Yep. So, I guess in terms of top three suggestions, I would say the first thing is to connect. So, to make sure that you've connected with other people with FND, because it can be quite a lonely experience for a lot of people who can't access help and spread all over the country. So, using things like the peer group that FND Hope UK run, and the other classes might be a nice way to connect with other people with the same experience.

I would say, to get informed and educate yourself about the condition. So, often you are the expert in your own symptom and condition, and often you're going to know more about FND than your healthcare professional, to be quite frank, in the UK. So, actually arming yourself with that information and going in with the knowledge, is extremely helpful in accessing the right care.

And I think there's something else about self-management in there. So, creating your own toolbox to self-manage your conditions. So, for one person it might be that they know they can only do, I don't know, one bit of physical activity per day and then they might have to do some mindfulness or they might have to do some stretches or whatever it might be. So, finding those patterns for yourself and incorporating that into your day-to-day life is helpful.

And things that we developed in partnership, the app called myFND app, which aims to support people to self-manage some of their symptoms. So, that might be a useful thing for people to think about downloading. But again, it is identifying what works for you versus others and incorporating that into your day-to-day routine.

Chantal Boyle:

Dawn, would you echo Chris' suggestions?

Dawn Golder:

He's done exactly what I've already written down to say. So, I would echo exactly what Chris has said, yes. I don't think I've actually put anything else. Apart from obviously trying to attend our online movement and wellbeing classes, which would be really helpful for them. And also, trying and see if they can register to attend our mindfulness or positive coaching course as well. So, it's a three-week course, I think it's about an hour and a half each week, but that will probably give them a lot of tools and techniques to be able to help self-manage. So, I would definitely recommend that as well.

Chantal Boyle:

And maybe to consider wearing the Sunflower for people who haven't-

Dawn Golder:

Absolutely. Yeah, definitely. Yeah, and I know a lot of our members do wear the Sunflower and they do find it helpful. So yeah, I absolutely recommend that.

Chantal Boyle:

It's been a real education today and I am incredibly grateful for you both giving me your time, because I know that you are both very, very busy people. I look forward to this going out and it's going to really support a lot of people who maybe didn't even realize that what they're experiencing is FND, and give them the pathway to try and get the support which you've so eloquently described today. Thank you very much.

Dr Chris Symeon:

Thank you.

Dawn Golder:

Thank you, Chantal.

Dr Chris Symeon:

The advice that we're talking about today doesn't constitute medical advice and it's really important that you speak to your healthcare provider about your specific issues.

Chantal Boyle:

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

Speaker 1:

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 disability Sunflower.