

PANDAS / PANS Informal Interview with panspandasawareness:
Text inside * is a tic. Text inside () is added to create clarity in this transcript.

Ticcers Unite: I will be asking my friend from the Instagram page panspandasawareness about their experiences. Please remember that we are not medical professionals, so this is not medical advice. This is to be used for educational purposes only. This was originally made in video format, but the audio and video didn't sync so my friend from the panspandasawareness page had the idea to turn it into a sort of podcast type thing with an image in the background so that is what we are doing. We hope you enjoy.

What is one thing you wish everyone knew about PANS / PANDAS?

Panspandasawareness: I think that most people don't even know about it. Secondly, a lot of people then just think that PANS / PANDAS is caused by strep, but it actually can be caused by any other infection as well. Like they are now thinking that with some kids, COVID is triggering it. So yeah, I think that is something people should know, as well that we have no control over it. We have no control over what our brain or our body is doing with this or how it's dealing with this infection.

Ticcers Unite: Yeah, definitely, that is a really good answer then. What have you found to be the most difficult symptom that you have experienced?

Panspandasawareness: Well, my symptoms have changed over time but out of all of the symptoms I have or have had, I think something I have had from the beginning on is the anger rage. I would say that is the most difficult for me because even though for me I had hallucinations for a short time and even though that was scary, I would say the anger rage because like you kind of just scare yourself because you just freak yourself out and then afterwards once you have finally calmed down there's an after affect where you just feel really sad about it from being angry. That can be hard because one second you can be really happy and the next second something sets you off and you're in an anger rage and I think that's quite hard to deal with.

Ticcers Unite: Definitely, the thing you said afterwards about being sad after, I think some people feel remorseful after as we kind of forget that we don't have control over it, so it is not really us doing it.

Panspandasawareness: A lot of the time we don't cut ourselves some slack because I am always quite hard on myself. I know I am not in

control, so I try and tell myself, treat yourself how you'd treat a friend' because to a friend you are going to be a lot nicer

Ticcers Unite: Yeah, that's definitely a good way to think about it. By having self-compassion and talking to yourself as if you are talking to a friend. It is difficult still, but it is a really good thing to try and develop. The next question is, how does it feel to go and have IVIG?

Panspandasawareness: Well I had about 6, 5 or 6 IVIG treatments so far and the first 3 I responded to very well, but that was whilst I was still on steroids. So, that meant that I was on steroids for 6 months, but after my 3rd IVIG I was coming down from the steroids as I had been on it for quite a long time and then every IVIG we had, we were doing it every 4 weeks it kind of got less and less effective each time. So, January was the last one because my OCD and the flare - I was flaring up more and more it was actually doing more harm than good. But yeah, and first... with the first 2 we saw huge improvements but that was whilst I was still on the steroids. As you can see my body changes its response to things but that also happens to a lot of people, a lot of kids and stuff. I think because IVIG does work and has good effects I would definitely recommend it if you are able to get it.

Ticcers Unite: Yeah, that must be really frustrating to have treatments work and the more you have to have it, you know do you ever ... does that bother you? Does that worry you?

Panspandasawareness: Yeah, because I also just get worried what if at some point, we have tried everything, and my body keeps on doing this. What am I going to do then? What if there are no medications kind of thing, but I have very good doctors and they reassure me that we won't stop until I'm healthy and they won't give up. I guess I just have to have some faith and hope, because otherwise every time I stop reacting to something or if something makes me worse it's hard because it's going to be a long journey. For everyone it is, and you just have to stay positive and everything. So, even though little successes like a treatment working I get overexcited and think woah this is it and then I am wrong, so I just have to kind of try and not worry too much about it and accept the way things are.

Ticcers Unite: Yeah, that's a really wise response and that's amazing that you have a team of doctors that are working to get you better - that's amazing. I think that you will find something that makes things easier for you. I really, really hope. It is confusing though because so many different things work for different people. I know you have made a little video about that on your Instagram.

Panspandasawareness: Yeah

Ticcers Unite: About how everyone is so, so different but yes, I really hope you do find something that can stabilise your symptoms and help you.

Panspandasawareness: Yeah, but I do have really good group of doctors but I'm one of like ... the less than 1 percent of the people who can actually afford this which is why it needs to change, because although I have a good group of doctors it's still going to take a long time and I can't... well I can imagine what it's like for people who don't have that and have doctors treating them who don't actually believe in it.

Ticcers Unite: Yeah

Panspandasawareness: It's just no matter what - it's hard, but if you have no support whatsoever, it's going to be even harder.

Ticcers Unite: Definitely yeah, *spinach* I feel like for some people it can sort of put them under a lot of financial strain and some people cannot access it so that is a big thing to point out to people watching this. It can be really difficult for people to get the care that they need so that needs to change.

The next question is from what you know about OCD and your experiences, do you think there are any differences between classic OCD and PANDAS / PANS related OCD?

Panspandasawareness: Well, either way it is quite a battle, and it can affect your life immensely. What I would definitely say is a big difference is... well I've been in a flare for quite a while - just the intensity fluctuating but the less of a flare that I'm in, or years ago when I was not in a flare then if its more classical OCD, I am able to control it more or work on it, but when I'm in a flare I have no control and I can't fight it or try to work on it. It's all just taking even more energy away from me so I would say that's a big difference.

Ticcers Unite: Yeah, that's really interesting and leads onto the next question I wrote down. What sort of response have you had to the CBT / ERP or other OCD related treatments such as SSRI's? You kind of did say already, but would you generally say it's different for people with PANDAS / PANS?

Panspandasawareness: I think it can help people - these kinds of therapies, but only depending on how far or how intense your flare is. If you are not flaring right that moment because even when you're not in a flare some of the learnt behaviours are going to be there, then I think it can be very effective or if you're flaring but "mildly" then it can be useful. When you are in a full-on flare it can actually make it a lot worse because you already have all those OCD's and everything and things going on in your head 24 / 7 so if then you are also seeing someone and you spend a whole hour once or twice a week just talking about your OCD's then it will probably make it even worse but that doesn't mean it doesn't work. It's just depending on your flare and stuff and everybody's different.

Ticcers Unite: Yeah, I think that's a really good thing to point out like everyone is very, very different with PANDAS / PANS, there is not a one size fits all so it's definitely different for everyone. For me, I would say that CBT and ERP didn't help that much but for some people it might, but then for me the SSRI medication has worked a little bit but for others it might not so there is so much diversity. I think that is a big thing, but that diversity can make it even more complex to diagnose and treat as well but yes.

Panspandasawareness: Yeah, as it's not straightforward.

Ticcers Unite: Definitely. So, what would you say is something that has really helped you on your journey?

Panspandasawareness: I think I would just say the support of the whole PANDAS / PANS community and even if it is just a little hello every day or just 'how are you?' it helped me because people who have PANDAS / PANS or know something about it or can relate - it's a lot easier and more helpful to talk about it than (to) somebody who might know about it but doesn't have it. They don't have it themselves because even though they may see how somebody's doing they don't know how it feels and even though a lot of my friends have a lot of different PANDAS / PANS symptoms, but to most things when they ask me how was my day and I'm like 'um well today was just ... I don't know - my hallucinations or my OCD's or whatever were non-stop' and things, then (there are) little things ... like little details that they can 100 percent relate to so I would definitely say support and understanding and like, caring for each other... yeah having community, a team - it gives you strength. Some people... your friends might have or have been through or are going through a similar thing and they can say they have. They can share

their experiences and say 'oh it's actually not that bad, even though I was really scared of this treatment' so yeah.

Ticcers Unite: Yeah, that's like a really good thing to say as well because I have found the same thing. Um, I made friends in the PANDAS / PANS community and it is actually really nice to have people to talk to who have been there themselves and know exactly what it feels like. Rather than ... Obviously therapy can be helpful for some people, but like when you are talking to somebody who has also experienced it, it's not like something someone's read out of a textbook. It's... they really do relate, so I think that's definitely something that helps. *Spinach*

Do you ever have any early signs of a flare before it explodes, can you tell if a flare is coming on or is it always very sudden?

Panspandasawareness: Hmm, well it's like both sometimes, I kind of... I guess sometimes I'm lucky and I can tell that something's coming on, but sometimes from one second to the next it will literally hit me. Usually, when I'm in a flare, some people they'll ... well a flare is usually for quite a while, and then you have these big, I guess... episodes that you could have every day - multiple ones. Yet, my flares will usually be on for quite a long time, but there will be episodes and they'll usually be quite strong for like days and that's even harder when you're already in a flare.

Ticcers Unite: Yeah

Panspandasawareness: Um, a few times before I did already ... I don't know how to describe it, but when I knew I was struggling and I would suddenly get this feeling just... I don't know it was just in my chest. even though I also have chest tightness. But, like this feeling, it's like something that's about to explode and I was telling my mum and she told our doctors, and they said this time we're just going to wait and see. A day or two after I was in a huge flare - an episode and I kind of exploded. I was upset because I was also then like... 'I've told you I told you guys and you didn't do anything about it' which made (me have) even more of an anger rage. Now, if I have that feeling my mum and my doctors - they react right away so then the intensity is less intense... even though it's still intense.

Ticcers Unite: Yeah

Panspandasawareness: But the thing is, with PANDAS / PANS is that it is something that happens suddenly.

Ticcers Unite: Yeah

Panspandasawareness: Yeah

Ticcers Unite: I *woo spinach* relate to what you said there as well as when I was younger it completely exploded, it was very out of the blue... um but then my flare at 17 I feel like there was a warning... a slight warning and then it exploded so I really relate to what you said there as well. It's really interesting, I feel like PANDAS / PANS is known for being sudden, although some cases aren't, but I think the most sort of hallmark PANS / PANDAS trait is if it's sudden onset OCD or sudden onset something related to that, like food restriction then it's well worth looking into PANDAS / PANS.

Panspandasawareness: Yeah, and sometimes I think it's ... even though it might not be sudden sometimes, it's hard to know which signs you should listen to or when to react. Just because someone's struggling doesn't mean they are going into a flare as sometimes we have bad days without being in a flare so yeah.

Ticcers Unite: Yeah, that's a really good point to say. What sort of thing would you say to a child who has just been diagnosed with PANDAS / PANS, would you have any advice?

Panspandasawareness: I think I would say ... you know it's going to be hard. It's not going to be easy, but like you will be able to do it because you are stronger than you think. You know, when you think you can't go anymore ... but you have already come so far because of the fact that you've been diagnosed because children sometimes go years and years until they get diagnosed but that's only if they get diagnosed - some kids never get diagnosed.

Ticcers Unite: Yeah, here we go... What would you say is the most *weeeeeee* frustrating thing about PANDAS / PANS?

Panspandasawareness: Hmm, I think my answers are always basically the same. That you just have no control and over it at all. Also, what's even harder is just that the illness itself is so hard as well but what's even harder is that the research isn't as advanced as it could be if there was more awareness and more people I guess choosing to do research about it. If just a few more doctors maybe each year would start treating it and learning about it, it would make a huge difference as there's many people out there on the waiting list which is so long because there are only a few doctors anywhere (who treat it). I think that's even harder, because the more doctors you have that treat it the more help you can get because they might have different views on it

and different ways and approaches to treat it. I think there are many things that are frustrating about PANDAS / PANS, so it's quite hard to just pick one thing.

Ticcers Unite: Yeah I definitely *weeeee* agree with the research thing. I think more research is really important because I know a lot of people... I think that in the medical sector they will be like 'wait for the evidence, wait for the research so we can treat it' but people are suffering now you know, and these people need help now.

Panspandasawareness: It's also kind of like with the COVID, people were suffering and you can see how they can do it ... like one can do it. Because of the covid thing, they were able to react fast. I mean yes covid is also quite big and important because it was killing a lot of people, but this also shows that... it doesn't mean we want answers this quickly, but it shows that things are possible.

Ticcers Unite: Yeah definitely, *wooo spinach* I do really hope that in the coming years more doctors research PANDAS / PANS ... more scientists research PANDAS / PANS, so that more doctors treat it and the waiting list as you said would be shorter. I think a lot of suffering would be prevented if people were helped earlier on, but yes.

Panspandasawareness: I definitely agree

Ticcers Unite: I believe this is the last question. So, would you like the way PANDAS / PANS is viewed, diagnosed or managed to be changed in any way and if so, how?

Panspandasawareness: Well, the doctors who are treating it, I think they are doing the best they can. I think there just needs to be more treatments, or just more options or just more support for these doctors who treat it and for their patients. Otherwise, the rest of it for changing how one treats and diagnoses it... It's more just people need to see these symptoms not as a behavioural issue, but as an illness. That's not exactly how you... it doesn't really apply to the treatment thing but yeah, I guess just more people need to know about it and more people need to show interest, but people can only show their interest if they know about something. They have to spread the word.

Ticcers Unite: Yeah, that's a really, really good answer. I think that is all of the questions now, but thank you so much for taking the time to answer these and to do this with me. It's really lovely to see you again as well.

Panspandasawareness: Thank you for letting me do this, and because honestly, we and many others are doing our best to help so anything we can do to help and improve is... Yeah, important

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