

PANS, PANDAS and Trauma - Understanding and Healing



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Transcript of 'Q and A'

Do you think children with PANS and PANDAS need a different approach from therapists or more just an understanding of the medical context?

I think that really, with children with PANS PANDAS, you need a therapist who is thinking about it from a health psychology perspective as well as a purely psychology perspective. So, health psychologists would be working more in physical health settings so they might be working with children with, for example, diagnoses of cancer or who have life-limiting conditions. They are more skilled in working with children who have those two parallel things going on. I think that what people are telling me is happening is that children with PANS PANDAS are going directly into the mental health route, where they are really just thinking about it in mental health terms. There is also something about the ongoing nature of the illness which I think requires more of a health psychology mindset. It is not something which is just over, it is an ongoing situation which could recur, and I think it has many more analogies with children who have physical health conditions than it does with the pure mental health side of things.

Siblings

I don't think that there is anything that I have said in this webinar which doesn't also apply to siblings, other than having the symptoms. But seeing your sibling go through this process is extremely traumatic. I would say that we often miss siblings. We often don't think enough about them. But I think they have the same need, the same need for stories to be told but they have the need to do that separately from their sibling. It is a bit like what I said about parents needing to process their own story without their child being there. Siblings also need to. They need to be able to say 'I'm really angry with how my sibling is behaving or with how I was treated, or I am really angry that my parents did this' and they can't do that if they are worried about upsetting someone else or if they are worried about the repercussions of that. They need a safe space to talk about that which is just for them.



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What would you suggest for a child who sees their sibling as a threat due to their OCD/ sees them as a risk so responds with violence? And what about when a child with PANS or PANDAS continually tried to control their sibling and how you can try to mitigate that?

So, both of these things I would do a story with. The one about siblings who aren't washing their hands well enough is a perfect example story. You can make sense of that. So... 'once there was a child who got very ill and got really worried about germs ... and then what they did was whenever they saw their sibling not washing their hands properly, they started to feel really angry and anxious...' You want to make sense of what is happening for that child. So... 'then they felt really at risk, so they did this BUT they were wrong'. Sometimes I have in my stories 'but their brain made a mistake, their brain thought these things were really risky, and that is understandable because in the past it had been really risky but now it wasn't'. So, you try and make sense of what has happened for them and then show them another way. You could then say 'so when this happens the child felt really really anxious and they thought I have to get out of this situation, BUT ... then they remembered... this is my brain making a mistake. I can go and run around instead, or I can go and stamp my feet instead. I can go and get out this energy in some other way'.

And I would say they are controlling their younger siblings because that is a way of feeling in control, so when something like this happens, and I have talked a lot about not feeling safe, I think young people often don't feel safe, but they also don't feel in control and that is really destabilising for children. It's like the ground is loose beneath them, they don't know where they are. It is really hard when they are controlling a younger sibling but again, I would name it. I would say 'I think it makes you feel better when you do this. It is a way of dealing with anxiety'. But I would step in, even if they are very very angry and distressed, I would step in to protect the other child because you have to draw that boundary around your younger child even if the other child is furious about it and even if means literally putting your body between you and the other child because you don't want the younger child to grow up thinking no one will stand up for me, that no one notices this is happening to me. I know it is really hard. It is not easy in any way at all.



How to manage the unpredictability of both the condition with its flares and also the unpredictability of how professionals may respond to your need for support, both for the person with PANS/PANDAS and their family?

One of the things parents can do for their children is they can be the safe person who maintains the feeling that we are going to get through this, things will improve, even if, right now, we can't see how they are going to be better. And for parents I think it is really important, if you can, to find someone who can be that for you. Whether that is a friend or family member or whether it is a counsellor that you pay. Someone who can be there and listen to your fears and who can maintain this steady base for you. I think that can do a lot to help things become less traumatic. If you have this kind of anchor, someone who is anchoring you, who can say 'You are going to get through this, it's going to be alright, we don't know how you are going to get through it but you are'. And I think that's where the diagnosis side of things comes in. You don't know how you are going to get through it, you don't know what path you are going to have to take and I think that, often, families do a lot of kind of hanging on ..'If we get this then it'll be better. If we get this, then it'll be better'.

I think that one of the things that can be helpful, and again to use metaphor, is to think about it as if you are going through a really difficult journey or maze, with twists and turns and obstacles and bumps, but probably there isn't going to be one magic thing. A diagnosis might take you in a different direction, but it won't solve everything. Nor will a different school or starting to home-educate. It will also just open up different paths and sometimes I think just allowing yourself to think about it as making our way through something rather than solving it. It's about how we get through this together.

How to manage self-harm which happens as a reaction to trauma?

Self-harm is really complicated, and if you have a child who does self-harm it is always better to seek help, because I think you need someone who can properly look at that situation and think about what is going on because I think it can be a self-perpetuating cycle. Basically, what happens is that some things like self-harm can start off as a response to trauma but once children or young people start doing it has this kind of cycle of its own. They feel a bit better; it releases tension, and it can almost become cut off from the original trauma. It becomes something which is a cycle of its own. So, I would try to get some help.



Somebody has raised the question about sleeping in the bed/co-sleeping since PANS onset...

My general advice when people ask about children who are co-sleeping is that if they need it, and they want it then I probably would not be pushing them out. I would be making the space so they can move out if they want to, but I wouldn't be pushing them out. But that is my particular stance. My experience has been that, generally, as children get to puberty they do go back to their own space. That they want to be in their own space. So, it is often children at say 9 or 10 that people are most concerned about. They say, 'I am really worried that my 9 or 10 year old wants to sleep with me' and pretty much my experience has been that when they get to 11 or 12, they tend to go back to their own beds. People are often worried that they are going to end up sleeping in their bed forever. I haven't seen that happen. What I have seen happen is that older children will come back to their parents' bed for a bit if something terrible happens and I think they are just looking for safety. Think about it in terms of their trauma and their brain. Basically, you make them feel safe. You mean that they can sleep, and they don't feel safe yet on their own and that is natural given what has happened to them so I wouldn't be pushing them out.

Within the context of PANS and PANDAS, how does trauma impact upon rituals and should we challenge the rituals?

It's tricky because it is very difficult to know, because it is very specific to each child. If you go and have treatment for OCD they will tell you to challenge the ritual as I am sure people know. Basically, trauma and rituals, trauma and OCD, I would see as similar to self-harm. You have the trauma, you have the amygdala response to it, you feel really unsafe, you feel in danger all the time and you then do things to try and help yourself feel safer. So, you control your sibling for example, or you start to do lots of rituals, because all of those things help you feel a bit safer and the actual, original problem was the trauma but now we have all these rituals which are a way to feel safer. The problem is, if you are challenging the rituals without making sense of the trauma, you are just making someone feel less safe, without providing another way for them to feel safe.



So, you might want to be thinking about what are the ways that they could feel safer. Is there world actually safe now? Are they happy at school? Have we got a safe and containing environment now within which they can relax? Or are they still actually quite unstable and this is their way of coping? You could talk to them about that ..'I think this is your way of coping when you don't feel safe'. And the way that I do it, because lots of children do not like parents commenting on things like this at all, is that I comment on myself. So I say, for example with a sibling, 'When I am feeling unsafe, or when I am feeling really worried about things, I start telling other people what to do'. I start saying 'Why haven't you done this? You have got to do this!'. So, I make it about me and then they can laugh at me and say I'm ridiculous. But they are able to hear it in a way that they couldn't if I had said 'When you feel like this, this is what you do with your sibling'. Then they would have said 'No I don't! Stop being silly!'. I do that a lot actually. I talk about myself in order to talk to them about themselves.

What about EMDR for PANS and PANDAS?

Well, I'm actually an EMDR specialist and a lot of what I have talked about today is derived from what I do with my EMDR clients. I use imagery and stories in EMDR, so I would say it could be quite helpful and is non-intrusive for children because you can use stories, so it doesn't necessarily demand much of them.