

PANS, PANDAS and Trauma - Understanding and Healing



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Section Three **Stages of healing**

What Can We Do?

When something terrible happens and then it is over – or at least things are a bit better – then there is a strong temptation to push it all away, not talk about it about and definitely not talk about things which might upset everyone again. This is totally understandable, and it's what most families do. Things are back on an even keel, and so you don't want to risk rocking the boat again.

There's a problem with this however. Remember all those memories that get stuck in the amygdala at times when you felt under threat? Over time, lots of those memories will become like other day to day memories. Right after a terrible event happens, almost everyone feels jumpy and unsafe, but as time goes on, many people will recover and start to feel better. They relearn that they are safe and that the world is (mostly) not full of imminent threat.

However, in order for this process to happen, we need to be able to think about what happened. It's a bit like all the memories were crumpled up and shoved in the cupboard under the stairs, and we need to get in there, get the memories out, smooth them out and put them where they belong – in the past.

When we try not to think about it (or talk about it, or write about it), we can stop that process from happening.

Now, this doesn't mean that you need to be talking or thinking about what is happening during a crisis. When you're in a crisis, the priority is getting through it with everyone safe. Putting one step in front of the other, keeping going, just getting through it.



This is about when the crisis has passed, and when there is a strong temptation to ignore it all and push it back in the cupboard under the stairs.

Circles of Connection

There are three steps to helping children process what happened to them.

1. Connect with yourself
2. Connect with your child
3. Connect with what happened

Connect with yourself

The first step is for you, as their parent, to connect with what happened for yourself. Separate to your child. It is absolutely essential to find ways to look after yourself because you are your child's emotional safe space. You help them know that things are going to be okay – but for that, you need to care for yourself enough so that you can hold onto the hope that things will be okay.

This connection with yourself might involve writing your story, talking to a trusted friend, talking to a counsellor, talking in a support group – you need to allow yourself to think about the worst parts, away from your child.

Connect with your child

This part depends on what is happening with your child at the moment. If they are in crisis, your role is to calm and soothe them, to try and find the tiny moments when things are better and you can connect with them. This means joining them where they are – if that's on the sofa watching YouTube, then that's where you need to be with them. If it's playing Minecraft, then you do that. Relationships can become very strained when there are extra pressures, and this is about showing your child that you are there for them, no matter what.





For children who feel unsafe and under threat, the response of the adults around them can make a huge difference. If they think that you are also out of your depth, it will feel much scarier to them. If you can look calm and containing and you can tolerate their emotions, that can make all the difference (even if it doesn't seem so in the moment). Reflecting on their emotions can help here. Things parents can say include.

- It's okay to feel this way.
- Your body is reacting to what happened.
- You'll feel like this for a while and then it will pass.
- It feels really overwhelming right now and it will get better.
- I'm here with you.
- Let's shake and move our bodies.

Or sometimes the right thing is to say nothing at all, but to be a consistent and calm presence.

Connect with what happened

This can only happen when things are calmer. It's not possible to process trauma and calm down our survival system in the middle of a crisis – we need our survival system then. It's useful.

But when things are a bit calmer, and you aren't in crisis anymore – this is the time to think about connecting with the experience.

The research on healing from trauma shows that healing happens when we have new experiences which show our body and brain that we are safe again. This can involve opportunities to talk (and play) about what happened, and to feel heard. It can involve drawing pictures of what happened and revisiting the story – but this time the story has an ending. Having a calm and containing person listening to our distress and helping us see that we are safer now can make all the difference.

Becky Whinnerah (@BexGoneWest) drew me an amazing depiction of the three circles of connection, all packed inside each other. In the middle is connecting with yourself, then with your child and, finally, with what happened.





Here's another story about a family's experience.

DAVID

When David was 11, he got ill and his throat got badly infected. When he recovered, he went back to school and didn't seem to have quite recovered - he was tearful and moody. His parents thought it was the start of puberty. A few months later he started crying and said that he just felt sad all the time, and nothing felt like it had any point. He said he felt like he was distant from everyone. He said he wanted to just get away from everything. He would send text messages to his mother all the way through the day saying he felt awful and didn't know why.

At home, he was irritable and made his siblings keep to new rules about cleanliness, washing his hands several times an hour. He wouldn't touch anything without washing his hands before and afterwards. Mealtimes became a trial, with David shouting at anyone who spilt anything or made any sort of mess.

His parents took him to the GP who said it was mental health and referred them to CAMHS and recommended a parenting course. Things started to get worse after David got a virus and he said he was seeing blood dripping down the walls. His mother was terrified and rang the GP who chased CAMHS but the waiting list was still months long.





David stopped being able to attend school and school sent letters saying that he was a persistent absentee, and his parents could be taken to court if this didn't change. David read them and reacted very badly, hitting himself and saying he wanted to die because everyone hated him. The school wouldn't support their request for EOTAS as they said the problem was behavioural.

His parents sought private help but didn't know who to turn to. A psychologist suggested that it was anxiety and said he shouldn't be allowed to avoid school. Blood tests were done but nothing really showed up. A paediatrician said that everyone was a bit anxious after Covid.

It was through internet searches that David's mum came across the PANS/PANDAS support groups and found a private consultant who would take David's problems seriously.

David and his family were all left with significant trauma symptoms. They felt on edge all the time. David's mum had flashbacks to getting letters from the Local Authority. His dad was furious with how they had been let down. David felt terrible about himself and what he had put his family through.

Glossary

EOTAS - Education Otherwise Than At School

CAMHS - Child and Adolescent Mental Health Services

