

PANS, PANDAS and Trauma - Understanding and Healing



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Section two **Trauma and PANS and PANDAS**

What does trauma have to do with PANS/PANDAS?

There are many things about PANS PANDAS which cause children and their families to feel under threat.

There are the symptoms, which are often sudden, unexplained and intense. These can be frightening in themselves. Children go through a sudden dramatic change and may have terrifying experiences. Then there's the unpredictability of whether it will happen again, leaving everyone feeling unsafe.

However, it's more than that. There's also how other people respond to the symptoms – typically not recognising the changes, sometimes blaming parents or blaming the young person for their behaviour. It can take years for anyone else to recognise the problem, during which time the child and their family feel very unsafe, and often let down by those around them.

School can be a particular problem, with teachers not understanding why a child can't do things they could do before. Children may hear negative messages about themselves, and the symptoms are often treated as 'bad behaviour' meaning that children are punished for them. Parents may be told that they are the problem, for not insisting on 'better behaviour' or making children go to school every day.

School attendance polices then come into play and these can be traumatising in themselves. Parents are told they must force their children in, they may be threatened by legal proceedings, and some children have been told that their parents will go to prison if they don't attend school every day.



Wider society may also not recognise the problems and so families lose their friends and the support of their wider family. Some are accused of FII (fabricated induced illness), of inventing and exaggerating the child's symptoms. In the worse cases, social services may be involved and families have been accused of abuse or neglect.

None of this helps children and their families feel safe. This means that families can be dealing with multiple sources of trauma.

Symptoms → Response of others → Feeling of lack of safety and being under threat → Trauma

Many families feel that the whole way that they see the world has changed. The things which they thought were safe and constant are no longer so, and it turns out that the safety net they thought they had was not there. Parents and children spend a lot of the time in high arousal, unable to relax.

This means that lots of memories get stored in the amygdala. Our amygdala then uses these memories in order to refine the way that it perceives danger – and this is a problem.

That's because the amygdala acts as an alarm system for our brain. It detects danger and sets off the survival system. It uses earlier experiences to predict what will be dangerous or not. It's over-inclusive – it's better to be safe than sorry.

This means that children and families can be in a situation where their amygdala alarms are being triggered all the time, by apparently minor things.

Here's a story to show you what I mean.

CARLY

Carly was seven when she got a severe sore throat, high temperature and a rash. When she recovered, something had changed. She started washing her hands obsessively and was really fussy about food. She stopped being able to make decisions, breaking down in tears over what cereal to eat for breakfast. She started worrying about school and had severe separation anxiety. After school, she would be violent and aggressive to her siblings who started to be afraid of her.





The GP said it was behavioural and suggested a parenting course. Rewards and sticker charts seemed to make things worse. She started to cry every day. School said she was fine, and the GP made a referral to CAMHS who had a waiting list of over a year.

Bedtimes were awful, with Carly running around the house unable to calm down or rest. Her parents disagreed on what to do, with her mother sure there was something wrong but her father thinking that it was a lack of boundaries. They started to fight.

They had appointment after appointment with the GP who said there wasn't much she could do. Carly started picking at her skin and pulling her eyebrows out. She started to find clothes excruciatingly uncomfortable and would strip all her clothes off the moment she got home. She would refuse to leave the house and would bar the door when her mother tried to go out.

By this point the whole family were on eggshells. Her younger brother had started to wet the bed and wouldn't sleep alone. Her parents were hardly talking to each other, and her mother was on the verge of losing her job after so many calls from school.

Carly was referred to the autism pathway and was given a diagnosis of autism, but her parents weren't convinced. She'd shown no signs before. Now, when they went to the GP, the GP would say that any problems were due to the autism and related anxiety. They went on autism parenting courses, but the strategies didn't help.

It was through her father's colleague that they first heard of PANDAS and the GP said that this was controversial. They paid for a private consultation with a consultant who prescribed antibiotics which immediately made a difference. However, the symptoms came back again when Carly got a virus. They continued to get better and worse.

Where's the trauma in Carly's story?

Carly and her parents felt on edge all the time after this experience.

There are the symptoms themselves which were unpredictable and distressing. Both Carly and her parents were left with a strong response of panic to any sign of separation anxiety. Carly was left terrified of germs and sore throats, which led to more hand washing – which frightened her parents more.

Carly's parents had had many bad experiences with medical professionals, and they started to have a danger response to their GP surgery. Emails from school triggered the same response and Carly's mother would have nightmares about getting an email about attendance.





Carly's siblings had also had a time of feeling unsafe, when Carly attacked them. They would flinch whenever she raised her hand, even in play - which in turn would upset Carly, which would upset her parents.

The amygdala is triggered by matches to previous experiences when you felt under threat – in this case, illness, sore throats, doctors, phone calls and letters. When that amygdala alarm goes off, we go into survival mode, and this means that lots of parents and children are very reactive. Tiny things can set them off and reactions often feel out of kilter with what has happened.

One way to think about this is that it's like children and families are sensitised to the world around them. They don't feel safe anymore, and so everything can feel like a threat.

Then there's a vicious circle, because feeling under threat can mean that you have more experiences which feel dangerous (because everyday experiences feel dangerous now), and then those memories get coded in the amygdala – leading to feeling even less safe.