

PANS, PANDAS and Trauma - Understanding and Healing



Dr Naomi Fisher
Clinical psychologist

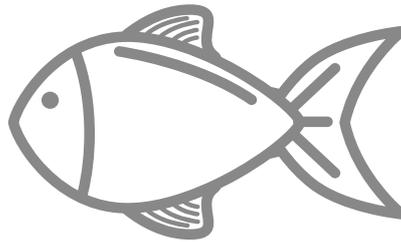
Section Four Practical ways to heal

So how can we help children like David (from our story in section three) and their families heal?

We're talking about the outer circle now – connecting with what happened. This should only happen when things are calmer and more stable. If you're in crisis, then that's the time for calming and soothing and looking for support for yourself.

A useful acronym to remember the ways to heal is FISH

Feelings
Imagery
Stories
Hope



Feelings

We need to make space in our life for our children's difficult feelings. Parents are often so pleased when things are better that they don't want to mention the hard times – they try to smooth things over instead. This can mean that children don't get a chance to explain how they feel – because it can be upsetting. It's important to allow our children to have all their feelings about what happened, anger, frustration, shame, anxiety – all of these things are common.

Hearing a child's feelings is often upsetting for their parents which is why looking after yourself is so important. Sometimes it can be useful to find other adults who are less emotionally involved and who might be able to hear a child's distress. The main idea is to focus on empathy, not fixing. Parents are often so quick to try and fix a child's emotions or to make things better – but here we're trying to give them the space to explore what it was like for them.



Here are some examples of how parents often respond – and what a response which hears the children’s feelings might look like.

Child: I hate my life

Parent:

Instinctive response: Oh, you don’t really feel like that! You seemed happy earlier in the park.

Empathic response: You are feeling really terrible about your life. I’m sorry.

Child: I felt trapped and like I was in prison.

Parent:

Instinctive response: Oh don’t be silly. You know you could have left if you needed to.

Empathic response: That sounds horrible.

Child: I can’t do this any longer.

Parent:

Instinctive response: Well, we all have to do things we don’t like sometimes. I don’t want to do it either but I am.

Empathic response: It feels like you just can’t go on. I’m here for you.

Warning – empathic responses often bring on more emotion and this can scare parents. They think that this means they are making things worse. It isn’t that, the emotions were there anyway, it’s that the child feels safe to express them.

Imagery

I’m a big fan of using imagery to help us to feel differently about things. One really simple way to do this is to practice bringing something into your mind which helps you feel safe and good about yourself. For adults, that might be a calm beach, for children it might be their house in Minecraft or playing football.

Often when things are bad, we try to talk ourselves out of our feelings. This doesn’t work with the survival system, because it’s a very primitive part of our brain which evolved before language. This means people get stuck fighting with themselves in their head.





Imagery comes in at a different level – instead of fighting your feelings, you imagine a place where you feel safe and calm, or happy and engaged. You take some deep breaths and visualise it, and then notice all the sensations in your body without judgement.

You can also use other senses rather than just imagination. Music can be a great cue to help you bring yourself to another emotional state, and I know people who use YouTube videos of music playing so they don't have to bring up an image for themselves. You can practice doing this at times when you are safe, and then in the future you will be able to use it to help stay calm when things are hard.

Stories

Making sense of what happened to us is an important part of moving memories from the amygdala. Usually when we are in a crisis, nothing makes any sense. There is no narrative, it's all just happening. This is particularly true for children who may not know all of what is going on.

One way to help with this is to use story telling. You could pick a metaphor for your family's experiences – maybe it's a stormy sea (with calm periods), or the weather, which gets wet and windy and then less intense again, or a road which can be bumpy and which has obstacles that you need to get past. Just doing this can help make more sense of what you are all going through. If your children want to get involved, you could draw the metaphor together, or make it out of clay, or even model it out of cardboard boxes. It's important that the metaphor has the idea of progression, even when things are tough, and that the bad times are things to get through, not ends to the journey.

You can also write stories for your children, particularly your younger children. I'd make stories short, at their level, and they need to have three parts. The happy beginning, the middle where hard things happened, and an ending where things improved. The ending is really important. You don't want a story about how things got worse and never got better. If things aren't that much better now, make it aspirational and put in tiny things like they got a nice Christmas present, or they made a new friend.



Here's an example story.

There once was a little girl who was born and her Mummy and Daddy loved her very much. This girl had some difficult things happen to her, like everyone. She got ill, and then suddenly she felt very different. She found it hard at school and there were lots of things she felt she had to do. She had to touch the door knob lots of times before she could go through it. It was very frightening for the little girl. She didn't know what was happening. She was very upset and angry.

The little girl didn't know she had something called PANS which had affected her brain. That was making everything difficult for her. When the doctor found out they gave her medicine and she started to get better.

The little girl got better but she was still scared it might happen again and she still felt frightened. When she was frightened she tried to tell everyone else what to do because she didn't feel safe. Then she got in trouble and felt terrible. Sometimes she did get ill again but she always got better again too.

The little girl started to grow up and she realised that she could learn and do lots of things, even though she sometimes got ill. She realised that she was good at lots of things and she had friends. She sometimes got sad and angry but then her Mummy helped her calm down again. She knew that she was safe.

The End.

I always write stories about 'a girl' or 'a boy' (rather than their name) because after I read the story I ask them if there's anything they would like to change in it. Some children won't change anything in a story if it's about them, because they say that wouldn't be true. Changing the story doesn't have to be true. This is where fantasy can come in – their favourite superheroes can arrive, or someone can come in and do magic – that's fine. Write it in the story and read it again whenever they want to. They can illustrate it if they want.

Some children will say 'that's me, I want my name in it' and that's fine. Put it in. Be led by them.

Older children and teenagers are unlikely to want you to read them a story, but you could still encourage them to tell their story. They might want to make a graphic novel, or a podcast, or a YouTube video. They might not want to do that at all – in which case don't force them. They need to feel in control of the process. You can just let them know that lots of teenagers find it helpful to think about what happened in a creative way. I know of teenagers who have written songs about their experiences or done art work showing what it was like.





Hope

Finally we come to hope, which is perhaps the most important thing that parents can do. Keep hope alive that things will get better and that we will keep going on. Children have a much shorter life experience than adults, and they really don't know that it won't be like this for ever. Things will change. So you need to hold onto that hope for your children – and for that, you need to find people who can offer hope to you.

You can't be the emotional back up for your children if there is no support behind you.

To summarise

- PANS/PANDAS is very frightening for families and children.
- Symptoms are frightening in themselves and then the response of professionals and other adults can make it worse.
- This can result in trauma for parents and children.
- When a family is in crisis, the important thing is to stay as calm as possible and get through it.
- Healing can happen when the crisis is over, and it starts with connecting with our feelings and with parental selfcare.
- When things are calm, parents can use feelings, imagery and telling stories to help children to heal.