

Behavioural and Developmental Regression in PANDAS / PANS

Hey there! Today I am filming a very quick video explaining how behavioural and developmental regression can show up in PANDAS / PANS.

This is one of the potential symptoms that quite a few people experience, and I feel it is important for me to talk about because that term seems quite vague and it can show up in many different ways.

So some people may have interests that people younger than them usually have, interests that aren't really typical for people their age. This is something I have experienced; when I was 10 I would watch and listen to nursery rhymes on YouTube, and when I was 17 in a flare, I was watching Kipper, which was a toddler program. These are actually potential signs of regression in someone with PANDAS / PANS; I've heard other people have had similar things - their interests reflecting the interests of someone a lot younger.

So that can be part of it, but also taking steps back developmentally (that's the developmental regression part), some people may suck their thumb, use a dummy (or a pacifier, or whatever you call it), some people may not want to walk unless they are in a pushchair (depending on their age), so it can be a big regression, but the point in this is - people can develop PANDAS / PANS when they're a toddler and then it just looks like they aren't developing typically; or what it usually is, is if someone develops PANDAS / PANS when they're in school or even a teenager there

is a big noticeable regression - not everyone has this by the way but it's a symptom that you'd notice usually.

Talking as well, some people with PANDAS / PANS may regress in the way they speak. Some people may struggle with grammar, or may speak in just a few words at a time, or may speak in a way that others can't understand. Some people may even go non-verbal, I've seen this quite a few times, people going non-verbal due to PANDAS / PANS, and that can get better with the correct treatment. Some people baby talk, which is something that is quite commonly put in the diagnostic criteria (it gives a little example).

In extreme cases, I did watch one video of a boy with PANDAS who actually stopped walking, that would be an extreme case of developmental regression when something like that happens.

Creative regression is also quite common - someone may struggle to draw in as much detail as they usually would, someone may have drawings or creative outputs that look like they were done by someone a lot younger.

People may also seem more clingy and may feel like they need a lot more nurturing and attention as if they were a child; they may struggle to do things that people their age would usually do.

Having a loss of emotional regulation is also quite common for some people with PANDAS / PANS as

emotional regulation is something that we develop as we get older, but someone with PANDAS / PANS may go backwards on that as well, and this could also be down to the irritability symptom and the emotional lability symptom as well, but that's definitely something that a lot of people have issues with (the emotional regulation), and may react to something in what's perceived as an immature way because we just lose the ability to regulate our emotions, and just in general people may have mannerisms that reflect someone younger.

The thing is, with PANDAS / PANS regression, it isn't that someone wants to act this way, I mean regression can be a way to deal with anxiety and depression, which are symptoms of PANDAS / PANS, but usually the regression in PANDAS / PANS is not what we want to do, it just happens because our brain is being attacked - we genuinely regress and feel that way; we go into that state of kind of being younger in that sense.

But it isn't just the developmental and behavioural regression, people with PANDAS / PANS can regress or deteriorate in many ways, for example there's cognitive decline as well. People with PANDAS / PANS may struggle to think clearly, we may struggle to focus on things, we may have academic decline where we struggle to do the work we once did, we may struggle with maths, we may have a deterioration in our handwriting, so it isn't just the behavioural and developmental regression, there are different ways we can deteriorate in a flare, but regression is one of them.

But it is important as well to just distinguish the behavioural and developmental regression from the other symptoms like the cognitive decline and separation anxiety if it's clinginess, because with the diagnostic criteria it's important that you get it right because the diagnostic criteria for PANS is sudden onset OCD and / or food restriction plus two other symptoms, but with the other symptoms you need to find the right one, or you might say you have symptoms which you don't have or might go into another box.

I thought I'd just make this really quick video because it can be quite vague when people say behavioural and developmental regression, so here is an explanation. Bye!