



# Julia

*Julia was diagnosed with PDA by Elizabeth Newson aged 12 after her increasingly challenging behaviour resulted in school exclusion and social isolation. Now in her early 30s, Julia recounts the impact PDA (and her co-morbid ADHD) has had from childhood onwards and how increased self-awareness and connecting with other adults with PDA has helped her make sense of her life.*

When I read my old school reports now it was blatantly obvious I had PDA – they're full of descriptions of me wanting to negotiate, be in charge, not having any boundaries. One head teacher's comment was that 'the tail continues to wag the dog'. I went to a Montessori nursery because Mum realised playgroup wouldn't work for me, and whilst I had a few difficulties there it was nothing exceptional, especially given my age. However two weeks into reception class at school, I caused a real rumpus because I refused to colour Billy Blue Hat's hat blue!

Things went downhill from that point onwards. I had regular meltdowns, trashed classrooms, got into fights. A school nurse described me as a 'very disturbed and disturbing child' aged 7 or 8. I got fewer and fewer invitations to tea or to parties and from around 8 or 9 I was a bit of a social leper. Often the kids liked me because I was a bit nuts and fun, but their parents didn't. Much of my behaviour was outrageous, and people distanced themselves from me.

My brothers are much older than me and had talked about sex and used sexual terms in front of me quite regularly. When I was about 7, I told Mum and others that my brothers (who were young adults by then) 'interfered with me'. I meant this quite literally, that they were always there annoying me, interfering with my existence. Mum knew what I meant. But I told other adults who didn't. I had play therapy and because I was au fait with the mechanics and vocabulary of sex they concluded I must have been abused, but because I didn't disclose anything specific no further action was taken. My brothers were interrogated by social services. I didn't realise the impact I was creating otherwise I think I'd have made things clearer.

From the age of 11 I was kicked out of school, I had no social life, no friends, no future. I felt like a misfit; I was self-harming; hanging out with young men. I was placed on the child protection register because I was at risk from myself. After one self-harming incident Mum took me to A&E and, out of desperation because no one would take her seriously, she refused to take me home. I was admitted to a paediatric ward and after a day or two they called Mum and said "what do we do with her?" –

I'd tried to burn myself, cut myself and strangle myself with a TV cord. So they put me on Amitriptyline to keep me quiet. I started to see a psychiatrist and [finally Mum was listened to](#).

I was diagnosed with ADHD fairly immediately and started on Ritalin. Whereas I hadn't got on well with the Amitriptyline (I put on lots of weight and it made me feel like a zombie) I immediately benefited from Ritalin. [I was thinking in sentences for the first time ever](#). I could sit the whole way through a film and focus properly on the plot and the characters without getting distracted all the time by what was going on in the background. Un-medicated, ADHD would definitely be my biggest difficulty – I'm impulsive, risk-taking and hyperactive. [But with the ADHD under control, my autistic traits come to the fore](#).

Mum had always had a question mark over whether I might be autistic, and PDA was first mentioned by the psychiatrist who I was under for ADHD. Mum went along to the library, as you did in those days, and two weeks later the two sides of A4 which was all that existed on PDA were duly produced! [I was referred about a year later, though not without hassle, my Mum got the MP involved!](#) (I can't believe how little things have changed. Parents' understanding has changed, but the diagnosis route is worse if anything).

I was diagnosed by Elizabeth Newson aged 12 and a half. I remember quite liking her – she showed me her biscuit tin and it had lots of good ones in, all the ones you like not just those that everyone leaves til last! She also acknowledged Alf, my favourite soft toy who at the time was very real to me. This meant a lot, usually I had to remind adults to acknowledge him. [Looking back I can see that she earned my trust readily](#). I remember the process being quite fun, quite an adventure. My Mum told me that this lady might be able to help. I remember another lady with a stop watch timing my completion of tasks – my compromise was that I asked her to do the tasks as well so I could time her. I enjoyed that. Quite a few times I was quicker, and I could tell she wasn't just letting me win so that made me happy.

Diagnosis didn't change anything much for me at the time. Since strategies were already being implemented around me I didn't need to develop any myself. Mum had already discovered what worked and what didn't through trial and error, she had learned to negotiate and let certain things go. [Elizabeth Newson told Mum to take everything she knew about parenting and forget it](#). She even gave Mum her home phone number.

I had no further schooling for another 18 months. There was no ideal school for me. Mainstream wasn't an option, and the specialist autism schools weren't suitable as I was too intelligent. So it was decided I'd go to a Pupil Referral Unit. We were lucky, the headmistress there read the same two sides of A4 about PDA that Mum had read and spoke to Elizabeth Newson about suitable strategies. [Elizabeth Newson emphasised that it was important that I shouldn't be made to feel different, so they adjusted the rules at the unit before I arrived](#). I had a TA who I really liked, she was a bit mad and I liked it that she'd drive me to school herself. After discussing things with Mum and with Elizabeth Newson she decided from the outset that she'd be very much in the background and work with others as well as me rather than being glued to my side. [The PRU worked well – it allowed me control but in a controlled way](#). You could award yourself credits as well as the staff awarding you credits, and what you earned in the morning could get you rewards that same afternoon so there was no delay. This really worked for me, and also taught me an important life lesson, you have to learn how to give yourself credit for what you do. Whilst it wasn't perfect it

worked out OK, I felt accepted and understood, I had no exclusions and stayed until I was 16.

Post 16 I tried to get a diploma in pre-school practice. I did my observations and work placement but couldn't write up the reports so I failed. I knew what I had seen and done, what the objectives and outcomes were, but I didn't see the point in others knowing. No one could give me a good reason why I should have to write it up. The red tape annoyed me. I tried hair and beauty courses but got bored. I tried computing courses but I knew it all already. I've always been into crafts (this can often become quite obsessional, I'll have an idea on Saturday afternoon and by Monday I'll have the whole kit!) so I tried running my own market stalls selling painted glass or handmade cards, but I didn't sell much. I volunteered in a charity shop one afternoon a week, but then they wanted me to do more shifts and it all became too demanding so I gave it up.

I never really bothered to look into PDA - I used to tell people I had ADHD and that my brain was a bit funny – and only really read about it properly when I was in my mid-20s. I read the list of traits and recommended strategies and thought 'God, that's me'. I regret not looking into it sooner, being too stubborn to listen. I also realised there were others like me, though felt frustrated that all the information on PDA was for parents. So I set up an adult support group on Facebook, I waited for ages and came to the conclusion that I must be the only adult with PDA! Eventually after several weeks a few people joined, and now several years later we have 847 members. It was great to be able to say 'does anyone else do this ...?' and discover that I wasn't alone.

Researching PDA, being in touch with other adults with PDA and increased maturity led to self-awareness. For me self-awareness is the key. If you don't have self-awareness how can you modify or avoid things that cause anxiety? Society continually tells us we need to act in a certain way, we're forced to learn how to fit in. If you don't know why you feel anxious out there how can you deal with it? When you understand what's hard for you and why, you can make suitable adjustments. I have continuous pings or lightbulb moments when I look back and can see how certain things happened or why I felt in a certain way. All of a sudden once you have self-awareness your life makes sense.

But it also makes me feel a bit angry - if I'd been diagnosed aged 5 I might have a job now. There are a lot of 'what ifs'. Although I've accepted that I won't work I haven't accepted why. Demand avoidance is everything. Work is a demand too far. After a day of social interaction I might need a week of recovery. I can't work one day a week, or have a TA at work or have an office all to myself. I'd need too many accommodations. I'm too disabled. It's not like putting in a wheelchair ramp. And then with my ADHD I'd get bored too quickly.

I've been living with my partner Paul for 13 years. He's my primary support and is on call for me 24/7. He's an enabler, I need him there with me most of the time. I don't like being alone, it's boring. If Paul wasn't with me, I'd need someone to help with all practical aspects of my life – managing my money, filling in forms, making appointments, cleaning, cooking ... I even like to have Paul be in the room with me when I have a bath! It's not that I can't ever do these things myself, it's that sometimes I feel totally frozen with anxiety. It's like being post-viral, I literally cannot move.

We complement each other really well, he's very quiet and tolerant but not very organised, so I take him in hand without him rebelling. I do sometimes think he has PDA by proxy now, you can't live in the PDA environment and not come out unchanged. It's like nature/nurture in reverse. I've asked the council what services are available to help me, but it seems that because I'm able to articulate my needs nothing would be forthcoming. I do feel that the link between autism and intelligence needs to disappear. Just because we are intelligent and articulate doesn't mean we're not disabled and have every right to services to support us.

My support network also includes everyone on Facebook. I write a blog, I'm admin on the Facebook page for adults with PDA as well as many other Facebook groups, and have my own Facebook page. I also give talks and attend conferences. I have to prepare a long way ahead for these! My anxiety bucket doesn't empty naturally (or if it does it's very, very slow). I never want to get to the point where it's full as then my cognitive ability becomes too impaired and I can't cope. In order for me to be an adult for a full day and have all those people looking at me (if there are, say, 100 people in the audience that's 200 eyes!), I have to do nothing (literally) for a week beforehand. I don't dress or wash or cook, I have no social interactions, I don't do any of my hobbies. I sit on the sofa and watch TV. That way my anxiety is nice and low. I need another week's recovery time afterwards. If it involves an overnight stop, it's also a huge sensory as well as social demand. I've also just been appointed as a trustee for the North Devon Forum for ASC and ADHD.

I only have to use PDA strategies on myself if someone else is involved, otherwise I just do what I want. Despite the health risks, smoking is a great coping strategy – it's a way to get time out and I use it as an exit strategy quite a lot, even if I don't need a cigarette. A lot of PDA adults I know self-medicate in some way: smoking or vaping, drugs, alcohol. For me it's not the addiction to the nicotine, it's the emotional support and the comfort of the repetitive hand to mouth motion. It's good for my brain – it gives me time out and provides an opportunity for deep breathing!

If I could tell my younger self something it would be: 'It will be alright, you are loveable and your life is worth living.' I lost a lot of friends after 'coming out' as having PDA. I now only have friends, or cleaners or beauticians, who are PDA-friendly. I've deleted NT (neuro-typical) from my world, or at least all the NTs who aren't prepared to understand. I've found this to be quite a vital strategy and I'm much happier now I don't have to mask. Masking is a good coping strategy (you get in, get it done and get out) but it's exhausting. People don't get how much effort goes into it. On the surface they see me being capable, confident and articulate. Coping, to all intents and purposes. Under the surface there's a lot going on, it's hard and it's tiring. I also feel like a fraud if I'm having to mask, like I'm giving you this little bit of me but I'm hiding a whole lot more.

Julia works hard to raise awareness and increase understanding of PDA. More information can be found on her blog <https://memyselfandpda.com/> and her Facebook page [@JuliaDauntPDA](#). Adults with PDA can connect via [@AdultPDASupportNetwork](#).

Here are some of Julia's top tips:

- Start sentences with the word "please" rather than ending with it. "Please" warns you that a demand is coming and sounds more like an invitation, with room for wiggle. It gives the option to take some control back, by saying

something like 'only if you do it too'. I am always quite rebellious and really don't like signs ... if I see a 'keep off the grass' sign, I just have to put a toe on the grass. Whereas if it said please, that would be asking in a more respectful way. 'No entry' and 'Do not touch' signs create a shudder of disgust. I also struggle with recipes! Phrasing things differently makes the world of difference.

- Allow room for manoeuvre – I don't like menus and never order things as they are. I have to feel there's some room for negotiation or 'weaselling' as I call it. Be prepared to allow some weaselling when you're living or working with someone with PDA. Allow a feeling of control without losing control yourself. For example, if all the food in your household is healthy, you can give your child free reign over what to choose to eat.
- Rewards need to be granted quickly and acknowledge the effort if not always the results. I apply this to myself now at Slimming World, which must be the most PDA-friendly diet programme since it allows for quite a bit of flexibility. I always give myself a reward. Crisps if I've not lost weight, a chocolate bar if I have. When I lose half a stone I buy myself a new charm for my charm bracelet. Originally it was for every stone I lost but I decided this was too unachievable so I revised it. Parents could allow their child to award themselves stars – if they award themselves 20 when a parent or teacher only awards them one or two, this provides an opportunity to reflect and develop some self-awareness. And don't remove a reward that's been given! I've been on the end of those star charts at school and the feeling of failure never goes away – they never say 'Julia was good on Monday afternoon', what sticks is that by Friday I had nothing to show.
- Empathy is there, it just can't always come out. When you're so busy trying to manage yourself, it's hard to listen to others' needs as you don't have enough cognitive ability left.
- I don't like praise. A simple thank you will do, nothing OTT. It makes me uncomfortable. I feel anxious and under pressure that I might be expected to do it again, or do it better next time. It really makes my skin crawl. I also sense a sort of fraudulence in the other person. I don't trust it or know whether they might be taking the mickey. I don't know how to react to it and find myself saying 'thank you' back. If I feel praise was due but not given, I'll soon let you know!