



Riko

Riko was diagnosed with Asperger's aged 27, and through her own research realised that PDA was the best fit for her profile.

Looking back, Riko realises how much she masked her difficulties and found her own ways to accommodate for them, though she also experienced periods of deep depression due to not understanding the underlying reason for these difficulties. With the insight that has come from an accurate diagnosis and embracing the positives of PDA, Riko has found effective coping strategies and writes a blog to help others living with PDA.

I never knew I was different as a child. From a young age I did get the impression that people were scared of me, but I didn't know why. I also got the sense that I'd done something wrong at some point but struggled to remember what. I was the second eldest child of five to a mostly single mother and life was pretty hectic. We moved many times during my childhood and men came and went from the house regularly. Throughout childhood I was closest to my second brother, with only a year between us. We would fight and play with equal intensity. What I didn't realise until much older was how awful I was sometimes towards him. I literally beat him up and controlled him, but at times he tried to do the same back. We were like peas in a pod. *Looking back, I'm sure most (if not all) of my family had PDA.*

School for me wasn't a problem. Due to issues at home and my controlling, emotionally distant mother, I preferred school. Most of my younger years was like living in a fog, I didn't understand time or places or the order of things. I went with the flow. One memory that stuck out was when I had just started secondary school, my mother had introduced us to a guy and on a particular day out my best friend pulled me to one side. "My mum told me your mum is going to move in with him. She's going to ask you if you want to move too. You don't have to if you don't want to, you can say 'no' if it's what you want". I realise now that my friend was trying to look out for me but back then the question made no sense. I couldn't comprehend moving house and living with this guy. *The future had no shape for me, I just couldn't string together cause and effect.* We moved in with that guy shortly after.

Anxiety rarely showed as a child, though I do recall certain episodes where it did. One time my brother and some friends wanted to climb a tree and I nearly had a panic attack as I was convinced the tree would fall and kill them all. Despite my dimness when it came to life, I did have a wide group of friends, and an equal amount of bullies. Ironically I didn't know I'd been bullied until a teacher pointed it out in primary school. *I was the child who, unless you made it clear, just didn't 'get it'.* That should have been a sign of Autism back then, but *it took until*

the age of 27 for me to figure out I was Autistic, and another year of hard research before I came across PDA.

When I look back, I can see so many signs of PDA, but I masked so well and was oblivious to so much that I didn't come across as a 'problem' child, merely slow and dim. It was only through searching for help in relation to one of my son's behaviours that I came across Autism. I initially felt that the characteristics fitted both of us and it seemed to answer many questions, but the more I looked into it the more I realised it still didn't seem to explain everything fully. It was whilst watching the TV programme 'Born Naughty' that I saw behaviours that fitted both my son and myself like a glove and realised that PDA was the profile that made most sense for us both.

I now have a formal diagnosis of Asperger's and although I did try for a PDA diagnosis, the clinician said he couldn't diagnose it. It wasn't hard to get a diagnosis, contrary to what I'd been told. The entire thing consisted of a referral from my GP who promised I wouldn't get diagnosed as he 'couldn't see any signs of it', a total of 1.5 hours interview by two separate people who gave me some leaflets and said 'yes you have Asperger's'. After another referral and a half hour interview to try to get a PDA diagnosis, I was left with a letter stating they agreed that I fitted the PDA profile but couldn't diagnose. Having an Asperger's diagnosis hasn't really opened any doors for me, it was more of a confirmation that I was right. Sadly there isn't much help available for adults. However I do feel that being diagnosed myself helped in securing an assessment and diagnosis for my son, as I was able to tell CAMHS that he's just like me.

I do feel that I would have benefited from knowing about PDA earlier. In my early 20s I really struggled with being a single parent, all the housework and 'being an adult' whilst also doing a university course full time. If I had known about my difficulties I could have made changes and asked for accommodations. As it was, I struggled on alone with constant headaches, stress, financial difficulties and depression. I was trying to do far too much and with little help. Everyone attributed my inability to do certain things to laziness, and my struggles to keep up with my peers as lacking in motivation. At several points throughout my life I spiralled into dark depression amidst self-blame and self-hatred. All that could have been avoided with the proper understanding and help. I might also have had a better relationship with my family. It's so important that the correct diagnosis is given as early as possible, not just so that help can be accessed but so that self-awareness and understanding can come from within. We are able to do much more ourselves when we understand why we struggle, not just that we do struggle.

Finding out I am Autistic opened doors to other conditions I have struggled with throughout my life without knowing. It's amazing how we can adapt to our abilities without knowing the reason behind them, but it is even more amazing how much more we can cope when we understand. For years I would focus on people's mouths when they spoke, not knowing that I was doing this not only to avoid eye contact but to accommodate my difficulty hearing what was being said due to an auditory processing disorder (APD). Basically, I was lip reading.

Along with PDA and APD, I have also self-diagnosed with OCD, Alice in Wonderland Syndrome, Chronic Fatigue due to PoTS (Postural Tachycardia Syndrome) and Selective Mutism. The more I learn, the more gaps I fill. It's a relief to know that some things I've struggled with are normal (in terms of the conditions) and that while there are others that have the same issues, not everyone has the same problems. I now know I'm not 'normal' and that everyone else doesn't feel the same way as me. This helps me to be easier on myself rather than comparing what I am able to do against that of others. There is a reason, and it's okay if I don't meet society's standards, because I'm doing the best with what I have.

With PDA, the coping strategies that I currently use are a mix of ones I've figured out growing up, done unconsciously and ones I've learnt since finding out about PDA. I've been able to drop unhealthy coping tools – such as physically lashing out when things don't go to plan, self-harming when I can't force myself to do a task and putting things off then trying to do everything all at once and inevitably failing - and replace them with better ones because I know why some work and how to adapt them. Now I understand why things don't go as planned and [make allowances for failure in advance](#); I [accept that sometimes I just cannot do something](#) instead of getting frustrated; I try to do [small demands over a longer time period with plenty of planned downtime in between](#).

I've always been an independent person, I had to manage my own life from a young age. I've never liked asking people for accommodations but I think some have instinctively made adaptations for me as I can come across as younger and needier than I actually am. I don't like people helping me but at the same time I can expect people to do things for me, such is the way of PDA. I'm quite comfortable with my PDAness so would happily tell everyone I meet about it, except I struggle to communicate things like that. The most I end up doing is mumbling that I have Autism, and usually only if someone else brings the subject up first. It's annoying because I would love to shout it from the rooftops, but I literally cannot. [What does help is the fabulous support group for adults on Facebook](#). Everyone is so welcoming and it's refreshing to be able to discuss PDA and other everyday subjects with likeminded people. [It feels like I found my tribe](#).

I used to feel that life was a game, and you had to learn to play it right in order to 'win'. There are many paths to follow and if you land on a bad spot it can hinder your progress, but there are lots of good spots to land on too. I feel like I started out with a bad score but have managed to land on some pretty decent spots along the way. In order to try to explain how it feels to be a PDAer, I wrote a blog post. [For me it's like being in a poorly designed, constantly malfunctioning robot](#). The view is constantly obscured and none of the controls work like they are supposed to. Every button I press has an opposite reaction to my intentions. It's hard living this way, just when I get used to things they go and change. Every day I wake not knowing how I am going to act and what will happen. [There are still plenty of positives though and I wouldn't change my PDA for anything](#). My life might not have taken the path I intended but I am on a great course anyway.

When I was younger and more naive I had many hopes and goals for the future. I wanted to get a good job paying decent money (preferably where I didn't have to do much), I wanted a big house and lots of books, to be a successful author, lots of holidays and enough money to splurge every day. They weren't realistic. My goals have changed and I think not only are they possible but I am already achieving them. I wish to write more of my blog in the hope of helping as many people as possible. I wish to own more books (something never change) and one day publish my own book. I want enough money to lead a comfortable life with the occasional splurge and holiday. I know I've already written much and helped many people, I'm happy with that, so anything more is a great bonus.

My message to PDAers and people dealing with PDA individuals is to [learn as much as possible about PDA and other conditions](#). [Read, listen and be open to new information](#). I still have so much to learn about PDA but what I have learnt already has helped so much. We should never stop growing.

For further information about Riko, living with PDA and lots of very useful advice, please see: <https://dragonriko.wordpress.com/>