



Sally

Sally was diagnosed with autism in her 40s and through her own research self-identified as having a PDA profile. She felt empowered by the self-awareness that her diagnoses enabled and eloquently describes how this has helped transform her life whilst also explaining how PDA impacts her every moment. Sally also movingly recounts her struggles as a child and young woman and how she always felt like ‘a squiggle-shaped peg that fits none of society’s round holes’.

I’m a PDA Mum with a five-year-old daughter who is also autistic. I was diagnosed with autism just over three years ago when I was in my 40s. I found out about PDA after my diagnosis and joined a Facebook group for adults with PDA to learn more about it, as all the published information seemed to describe children, and aggressive volatile ones at that. I wasn’t like that as a child. I learned from the Facebook group that many others weren’t like this as children either but that I fit the PDA profile.

I was the middle child. My younger brother was born when I was seven, so I was the youngest child until this point and my older brother used to show me up all the time for being stupid and not knowing as much as him. This upset me a lot. In retrospect, I can see that my whole family was probably on the autism spectrum. My step father used to have terrifying meltdowns and my mum used to blame me for triggering them. My older brother was the golden boy and revelled in his superiority over me. *I felt worthless and that I was intrinsically bad, but I didn’t know what it was I did wrong. I used to enjoy making high-pitched noises and doing other deliberately irritating things to get attention.*

I went to playgroup for a bit, but got very upset when one of the women who ran it yelled at me for starting to go down the slide when another child was already on it. I refused point blank to ever go back. I didn’t really tantrum that I remember, apart from one occasion when I remember being in the spare room crying and scared and my step dad came in smiling and caring to see how I was and I angrily hurled a ride-on tractor at him. He left the room when I did this, leaving me feeling hopeless and abandoned. In general, I was very insecure and cried easily. My mum later told me I had been a very serious baby and didn’t like to be put down. I can remember staring transfixed at the telly as a tiny tot. I have exceptionally clear early memories starting from 6 months of age. *I was very fussy with food. A lot of food terrified me. I felt vulnerable; that it could harm me.* Also, I now realise that I am hypersensitive and many textures and tastes are very unpleasant to me. I was a very imaginative child, as was my older brother. *We used to pretend to be “animal everything” that could magically change into any animals we wanted.*

I'd been desperate to start school so I could be grown up like my brother. I can clearly remember my first moments in the classroom: I took a look around and decided that I [wanted the teacher's role!](#) School went very badly for me. I didn't mix well with the other children, though I didn't know why. They used to call me names that were effectively about me not being normal. I was rubbish at PE (I was diagnosed with dyspraxia aged 30) and was always one of the last children picked for teams. I used to play on my own a lot in my own fantasy world because the other children wouldn't play with me. Aged six, I [considered living in my fantasy world permanently.](#)

I also [struggled massively with being woken in the mornings for school.](#) No matter how tired I'd been, I could never get to sleep until the early hours of the morning. Discovering Delayed Sleep Phase Syndrome and being diagnosed with it last year has helped me to understand why. The closest I came to having aggressive meltdowns was first thing in the mornings, and I became quite specialised at skipping school as much as possible, first by feigning illness and then by playing truant and forging sick notes.

Life continued to be really hard. I can remember being about fourteen at home [looking at my hairbrush and feeling it was beyond me to pull it through my hair.](#) That there was no point: that I was so far removed from being socially acceptable that nothing I did would make me OK, so why bother to make any effort? My biology teacher actually commented that it was odd that all the other girls my age were making an effort with their appearance, but I wasn't. I couldn't communicate with him, but it meant loads to me that he'd noticed. The last day of school was the happiest day of my life, but I [pretended to be sad like the other girls because I wanted to fit in socially and be accepted.](#)

I made one friend when I was seven. She was a year older and used to tell me how to act, which I liked because I didn't know how I was supposed to behave, even though I so wanted to fit in. Like my older brother, she treated me like I was stupid and with little respect, but I didn't think I merited respect, so I put up with it. I craved company and hung around with her as much as I could. We got into shoplifting when I was eight and got caught. As we got older, my friend and I loved doing wild, reckless and sometimes illegal things.

She eventually became a punk and had a cool group of punk friends, all older than me. They all treated me like I was too naive and stupid to be a proper group member. I wasn't "allowed" to be a punk. I didn't care about the many risks I was taking either. I wanted to be a punk very badly and became one aged sixteen when I decided to "change" and not be bottom of the pile any more. The social group had moved on from being punks by then, but that didn't bother me.

I became very depressed aged nineteen when I realised that, despite my best efforts, I was still a social outsider. I practically worshipped social groups which I felt excluded from; their members were like rock stars to me. I had little time for people from other groups. The Groucho Marx quote, "I'd never join a club that would have someone like me as a member" resonated profoundly with me. My fantasy world now had evolved to one in which I was the most revered and valued member of a totally cool social group. In real life, I was chronically lonely and depressed. I got scared of people getting too close and shunned people who might have made perfect companions. I had something like a nervous breakdown.

[I was always extremely poor because I couldn't work. When I'd tried to work – either as an employee or self-employed – I'd felt driven to flee very quickly because I couldn't cope with the restriction of having to be in one place doing one thing.](#) I did quite well at college though, after dropping out of several courses, and was the first ever student in the college I went to be awarded 100% for art GCSE.

The law meant little to me, I'd continued to shoplift in compulsive bursts until getting caught twice in 4 days when I was nineteen. I got a boyfriend when I was twenty who wanted to set up in business selling drugs and the rave scene exploded around us. Initially I avoided it as a demand, but then got really into it and with my by then former boyfriend we became the centre of a dynamic social scene. I could only speak to friends from this wide group when I was high, I was too self-conscious and anxious to speak to them when sober.

We started organising our own raves, my ex would do all the phoning and social negotiations and I did the creative stuff. Following a visit from a friendly outreach worker who explained the concept of 'harm reduction' – just giving people the facts about drugs and allowing them to make their own decisions, which was an ethos I liked – I set up a stall at the raves with leaflets and free water. This caught the attention of our local drugs education charity who were very impressed and trained me as a drugs worker, but [I couldn't cope with the employment they then offered me because it felt like a demand](#). I earned a bit of money designing leaflets for them instead.

My life followed a pattern of periodic academic courses, which I did mainly because I wanted something to do, but no employment beyond odd bits of freelance which was all I could cope with. I suffered excruciating bouts of depression. I went to whatever free or cheap counsellors I could access on my very low income, because I wanted to feel OK and be able to get along effectively with other people.

The [first humanity-confirming diagnosis I received was of "anxiety, depression and irrational beliefs"](#). I was diagnosed with anxiety and depression on multiple occasions after this. I started university when I was thirty and, after seeing a dyslexia checklist, requested an assessment and was diagnosed with dyslexia and dyspraxia. My IQ was revealed to be 156, which I was told counted as genius. This meant loads to me as I still believed I was stupid from how my family had treated me and my ongoing social failures. I was diagnosed with chronic fatigue syndrome after becoming a mother. I came across a female autism traits list in my early forties and realised I fitted every trait on it. I asked my GP to refer me for diagnosis and was very pleased when the psychiatrist I saw diagnosed me. Having looked at my history, he agreed with my own belief that I'd had borderline personality disorder, but cured myself through all the counselling I'd been through.

My diagnosis meant that I felt [vindicated for the massive struggle I've always had in life and more self-forgiving](#) for the many social mistakes I've made. I was embarrassed to tell many people because I felt that there is a stigma attached to being autistic, and I felt a certain sense of shame and depression in that my goal of fixing myself completely to have no social issues could never be achieved, but [my main feeling was of elation. Self-awareness is something I value highly for empowerment](#) and this was a massive spoonful of self-awareness delivered in one go. My diagnosis came just in time for my Employment and Support Allowance appeal tribunal. Previously I hadn't been able to articulate why I'd never been able to work. Saying that I got claustrophobic and anxious hadn't swayed them, but announcing my diagnosis during my tribunal caused the panel to declare a recess and then announce that I had been placed in the support group. This was such a huge relief. I'd been so poor all my life. We'd had to move seven times in our daughter's first two years because of high rents and bills and had even been homeless for a time. Now, finally, the financial pressure had been lifted. I was also able to claim PIP and had this awarded too. It's great to no longer be living in poverty.

I spotted signs of autism in our then two-year-old daughter at about this time. My partner couldn't see it and her nursery manager couldn't see it. I knew she wasn't me, but I could see so much of my personality in her. My GP agreed to refer her to a child development

centre for assessment and they diagnosed her. We watched a TV series called 'Born Naughty' which was about children with developmental and behavioural problems to try and better understand our daughter. Two of the children featured had PDA. I was struck by the behaviour of the PDA boy they featured. He couldn't just walk with his mother, he had to go and do his own thing and went and climbed a tree. This is what I'm like. In my head I want to spend time with my family, [but every time it's like there's a negative magnet pushing me away and I just have to be free.](#)

I googled to find out more about PDA, but could only find descriptions of nightmare children having violent meltdowns. I hadn't been like this as a child. [I joined a Facebook adult PDA group to find out more. I found that I connected really well with the other members](#) and that PDA doesn't have to involve having violent meltdowns. PDA, in fact, actually described me really well. The profile revealed through chatting with the other members fitted me like a glove! I now clearly identify with having a PDA profile as well as my underlying autism. Whilst I was also relieved to be diagnosed with Delayed Sleep Phase Syndrome, this was nothing compared to my PDA. [PDA is a far greater impediment to me. It undermines everything I might potentially do.](#)

[My diagnoses have transformed my existence.](#) I am very thankful for my non-judgmental, accepting, supportive and un-pushy partner. He works in our daughter's school as a teaching assistant and is able to take her there and bring her home again. He gets her up every morning so I can get enough sleep and spends a lot of time with her during the days because – much as I adore her – I overload easily and need a lot of quiet time to recharge. My Chronic Fatigue Syndrome is a lot less severe as a result. I do feel depressed a bit that I don't keep the house spotless as I feel I SHOULD, but every single chore I do involves battling demand avoidance and I can only do so much. I do a few things every day (make the bed, Hoover the living room and cook dinner) and I realise that, although this may be much less than others do, it is an acceptable amount for me to do because of my PDA.

[Awareness of my limitations has given me the wisdom and confidence to set personal goals that I can keep.](#) Producing memes under the Sally Cat banner to communicate the reality of adult PDA is one fruit of my new awareness. The wonderful positive feedback I've had for my memes means loads to me. I like to help people and I like to achieve things. The feedback is also great because it makes me feel less alone with my difficulties. Knowing that there are others out there who identify strongly with the issues I describe is very uplifting to me.

I'm glad that my now five-year-old daughter has been diagnosed with autism and that her child development centre paediatrician has said he will consult about when best to assess her for PDA. I can see so much of myself in her, but without the self-doubt and low self-esteem that I had as a child. She has PDA, anxiety and autistic social blindness, but she knows she's lovely and loved. I feel that she has great potential within her grasp. She is very intelligent and creative and we can help her to navigate through her limitations to live a happy and productive life. [I feel that I would have achieved so much more if I had been diagnosed as a child. The confidence and self-awareness I have recently gained would have been with me from the start and I would have made better, more self-caring choices for myself.](#)

I have a lot to offer the world. Like my daughter, I am very intelligent and creative. I like to help people and I'm good with words (I was amazed to discover within the adult PDA group that word play and even renaming people is a common PDA trait!). [PDA for me is a rainbow spectrum of strengths and weaknesses; highs and lows.](#) Compassion-focused therapy and an eight week mindfulness course (both free through the NHS) have massively reduced my anxiety levels. I practice very brief mindfulness every day (my demand avoidance won't

allow for anything longer) and it helps tremendously. I feel much calmer and more grounded. The demand avoidance is still there, but I'm not as stressed about it. Awareness has also guided me to reduce the amount of demands I have in my life. Demand avoidance itself, I believe, is incurable, but it is less of a problem if I have fewer demands to avoid. The demand avoidance I'm left with is still exhausting; I have a constant battle to repress it, but my PDA has also gifted me with a wonderfully rich inner world of creativity and insight which, when channelled, I can gift to society as a whole. I want to be a contributing member of society, but I cannot do this as an employee. I am a squiggle shaped peg that fits none of society's round holes.

I feel I could achieve even greater things; even greater good, if there was support for people with PDA and autism in my area, but there is nothing. I was initially excited on getting my autism diagnosis that now I'd have support in life, but quickly found that funding cuts have caused what little support did exist to be axed. I would like to go freelance as an artist and writer, but I can't do this unaided. I can't cope with telephone calls at all (they cause me to overload) and I can't cope with paperwork and marketing; budgets and project planning. I recently tried to get an agent, but it's a flooded market and I don't have the people skills or demand avoidance quashing stamina to get myself heard.

If I could say one thing to others about PDA it would be: "please recognise and accept the existence of PDA adults. Our condition is hugely debilitating and we're not wired up to be good at fighting to be heard." If I could say one thing to my younger self it would be: "your struggles are real and you are worth loads. You are a squiggle shaped peg that is unique and amazing. Learn to love yourself and you can soar to great heights."

Sally produces insightful memes about living with PDA under the alias Sally Cat on her Facebook page: <https://www.facebook.com/SallyCatPDA/>