

James

James is 14 and kindly shared this extract he wrote about his experience of PDA. His insightful and honest account covers how PDA can be misunderstood; masking; school; the need to have 'demand free' time; the importance of trust in relationships; the impact of the Covid pandemic and what helps in terms of managing his demand avoidance.

Introduction

Hello, I am fourteen years old and at the age of twelve I was diagnosed with Pathological Demand Avoidance (PDA). I always knew there was something about me that was different when I was younger, but my family just saw me as a 'naughty boy'. Admittedly my behaviour was challenging but it could be made far more manageable if my family and friends understood me. I do not know who you are reading this right now, whether you have PDA, have a friend or family member with PDA or are merely curious about what it is. Nevertheless, I will try my best to give you an insight into the life of somebody with PDA. Also remember everybody is different, so everybody with PDA will have different experiences and ways of coping.

PDA and autism

PDA is a part of the autistic spectrum, so PDA and autism share many things in common. However, with PDA, there are also some differences.

For example, some autistic people have a tough time understanding and responding to social situations. On the other hand, people with PDA tend to overthink social situations and have constant anxieties about their social life and what to do and say in different outcomes. For example, I would say I have a particularly good social understanding and excel at making sarcastic comments and making people laugh. Despite this, when I am not in a good 'social mood', I can often miss jokes and struggle to follow conversations.

This is why people with PDA need time to recharge their batteries more than anyone else. Most people with PDA have a safe place where they can be themselves without having to answer to anybody's demands. My safe place is in my bedroom and I need daily time in there to calm myself and 'mentally prepare', for socialisation and day to day life.

Sometimes I see PDA as a war between separate parts of my brain; the neurotypical (non-autistic) side and the autistic/PDA side. This is because I like to play sport and meet up with friends, but the PDA side of my brain is like an anchor, stopping me from going and frustratingly I often do not have new experiences as I am extremely anxious and overthink whatever I am doing. For example, if my parents ask me if I would like to go swimming, I would immediately think of all the potential demands that I could have to worry about. However, if someone asked a neurotypical person if they would like to go swimming, they would not have this analytical mindset and

probably just focus on how much fun it is to splash around in a swimming pool. The 'Demand avoidance' part of PDA is the reason for this, and I will try to explain further about how it works in the next paragraph.

How and why do people with PDA avoid demands?

Demands are one of the toughest and most notable things people with PDA must deal with (the clue is in the name)! Unfortunately, there are constant demands throughout life. Even the smallest demand like brushing your teeth can push you over the edge, so it is no wonder people with PDA try to find excuses to get out of demands.

As a fourteen-year-old boy, a major demand for me is attending school. School is basically one big demand, so it is no surprise I have always hated it and had to take a break from it completely and then move due to my anxiety. If you think about school through the eyes of a person with PDA, waking up early, schoolwork, socialisation, homework, tests etc are all tough demands. This is a place where I am forced to attend most days for six hours and although I am naturally intelligent and good at socialising, when I am under this kind of stress, it is so easy to get overwhelmed quickly. This is yet again showing why people with PDA need time to themselves, demand free. Also, at the time I am writing this it is the school holidays because if I did it any other time, I would not be able to focus or concentrate.

Furthermore, people with PDA find change in routines challenging. For example, the other day one of my teachers announced we would be watching a movie because it was the end of term. Most people in my class are neurotypical and were delighted to hear this, however I struggle to deal with changes in routine and watching a movie has more demands than you think. For example, I had to sit still, be quiet and pretend I was enjoying myself to blend in with my classmates. This is why limiting demands on people with PDA is so important for their mental wellbeing and happiness. Even rephrasing a demand can take the pressure off it for somebody with PDA. You should try different approaches because every individual with PDA has their preferences and some make demands more difficult than others. I often find a bit of humour or sarcasm takes a bit of the pressure off demands but that may well not work with others.

Masking

As I have already mentioned, people with PDA are generally more social than some autistic people can be, and have a natural ability to mask their feelings and intentions. Many neurotypical people mask on a daily basis too, however, not to the same extent as somebody with PDA. People with PDA can use their mask to avoid demands and hide their emotions from people, even if they are trying to help. Shutting yourself off to help is not a good solution as it is always helpful to be able to talk to somebody. Unfortunately, I and a lot of others with PDA find seeking help difficult and often cope in silence. I used to have trouble with confiding and trusting others with my feelings, but I am getting better at speaking to my trusted friends and family. Although it takes a while for somebody with PDA to trust, I think all that is needed is patience and dedication to them.

Due to people with PDA masking, it can be hard to diagnose and it is often misdiagnosed. Despite masking making life difficult for me, it does have a couple of advantages. I am an expert liar and have an unreadable poker face! Anyway, masking

consumes a lot of my energy and too much of it can lead to mentally not being able to cope and meltdowns. I will not go into the details, but I will say this should be avoided at all costs as it is horrible to experience and can be traumatising. This is why it is so important for a person with PDA to trust somebody so they can let them know when they are finding things tough without embarrassment or excess stress.

As I have shown, masks can be very deceiving so people with PDA can be misunderstood by friends and family. For example, my parents did not know how to deal with me, so they told me off and sent me to my room. Of course, at this point they did not know I had PDA, so they did not understand they were making things worse for me. My parents did try and get me help and make sense of me, but they just did not know where to look. They also made me go to get some 'help' from this woman who basically told me I was a naughty boy and made me do stupid activities. Thankfully my parents did not make me go again after I made it very clear I was uncomfortable with the woman's methods. Due to the confusion masking can cause, it is almost impossible to tell what somebody with PDA is thinking and whether they are ok or not. Therefore, it is far easier to try to behave consistently with them and not stress too much about what you think is going on in their head, because you most likely will not be able to know.

Having PDA during the coronavirus pandemic

I am sure you will be familiar with coronavirus and the constant lockdowns and restrictions the government are putting on us. As somebody with PDA, I feel the pandemic has had positive and negative effects on me. For example, I do not have to mask as much when doing online school as I am in the safe environment of my room. However, the government keep being very indecisive and switching students like me from normal school to online school and I, like others, find this stressful. I appreciate the pandemic has been far more difficult for others and personally I think it gave me an opportunity to take a break from the social stress I usually go through. Having said that, I do like routine and I feel we have had no real plan of action all the way through coronavirus. Therefore, I was happy when we were told we could go back to school again as I still think I learn far more there. It still would not surprise me if we went into yet another lockdown but at this point, I am fed up with the changes and would like to get back to normal.

Conclusion

I hope you learnt something from me about PDA and I hope it was not too boring. I know this piece has not been perfect or professional, but I am just being myself. Thanks for reading. :)