



PDA & school avoidance with James transcript

Hello, I am James, and I'm 15 years old.

At the time of writing this, I am in the summer holidays before starting year 11.

I would like to share some of my thoughts on why school is so difficult for people with PDA.

I have been in school for over a decade now and most of that time I have not known why I find it so difficult as I was only recently diagnosed with PDA, which explains a lot.

According to a survey, around 70% of people with PDA do not attend a school and this statistic does not surprise me, as I know how hard it is to cope at school.

As I am usually full of demands and stress whilst I am in the school term, I am writing this in the summer holidays. This is so I can focus properly since, in my free time during school term, all of my energy has been used up by school to the point where I am exhausted from masking on a daily basis.

I would like to share my experiences at three different schools as it is an example of how challenging attending school, on a daily basis, can be for a PDAer.

In primary school, there was far less stress and as I am naturally quite an able student, I could cope well with the work and excelled in terms of my academic studies.

Also, there was not too much pressure on me at the time which made it less demanding. Despite this, I always felt something about myself was different in primary school from the other children and had a tough time overthinking about myself and my differences.

There were also several autistic children in my year, with classroom assistants. Although I noticed some similarities between me and the other children diagnosed with autism, there were also many differences.

For example, I was naturally able to speak and socialise with my peers and make friends, whereas other autistic children struggled to do this as easily. This made me blend in with the rest of my classmates and did not make me appear different on the surface.

I now understand this is due to a characteristic of PDA called masking, where we hide our feelings and usually appear socially able and advanced.

I also tended to feel I could only do a certain amount of socialising, and this is because my mask was exhausting my energy and I couldn't keep it up all day.

All of my school reports and parents' evenings were great in primary school, and I could tell the teachers liked me as I was well behaved and fairly easy to teach. However, at home it was a very different story. My behaviour was challenging, and I could not follow basic instructions. I also frequently had meltdowns and panic attacks.

This obviously puzzled my parents, since my school reports were nothing like this. My mum also knew at the time I was different to other children, but she had worked with autistic children in the past and could tell I was different from them too.

I also figured this out as I often overthought from a young age, and this meant I struggled to know who I was and why I was behaving in this way.

Overall, my primary school life was confusing for my parents and I. I struggled on a daily basis, with the mask I held up and the demands like homework and classwork. I also hated school from a young age even more than most children, although most of my issues began in secondary school.

Everybody, including me, tends to have a tough time moving up into year 7 as it is such a big change, and you are treated more like an adult.

I was very much overwhelmed by the change and found it difficult as this school was massive, and it was all so different from my little primary school. Despite this I still excelled in my academic studies and had a small group of friends.

During year 7 I had more panic attacks and meltdowns than in primary school, but I tried to mask them which as you can imagine was a nightmare. I felt uncomfortable talking to my parents about this because I was afraid people would find out about my problems and I'd never known anybody with similar difficulties.

Furthermore, sensory issues are common among autistic people, and I noticed myself struggling with them a lot during year 7. I hated the noise and the humidity of the lunch hall. I hated the flickering lights in all the classrooms. I hated how crowded it often was. However, I appeared, on the surface, to be coping well, even though, on a daily basis, I was out of masking energy and tired of socialising and the demands teachers constantly made.

What I mean by 'masking energy' is people with PDA can only mask for a certain amount of time because it is quite exhausting for us. We can recharge our masking energy by having calming time in a safe place where we are not overwhelmed by demands.

My calming place is my bedroom, and it is important I have daily uninterrupted time to recharge my mask in there.

Another sensory issue I had in year 7 was taking part in food tech. This is a lesson that only some schools do, but I found myself in sensory overload most lessons. For example, it is very hot in that classroom due to the ovens and the teacher was

particularly stressful since we had to prepare food in a certain amount of time which was quite demanding.

We also had to follow the recipe carefully which was also demanding. There were overwhelming smells, a lot of noise from my peers and I didn't have much space to work since it was a very crowded space.

Food tech was without a doubt my least favourite subject in year 7, especially because we were demanded to remember and bring in all the ingredients and equipment too.

It was very early days at this point but at the end of year 7, I was predicted to get top grades in all of my subjects. In fact, apparently, I appeared to be coping so well my mum went back into her job.

This forced me to become more independent and let myself into the house and do chores etc.

Year 8 was my worst year yet. All of my stresses built up and I had grown depressed and anxious. I had a lot of panic attacks and although it's not too clear in my head, I had hallucinations in school and more.

After a couple of months of year 8 I spoke to my mum more about my problems and she gave up her job and due to my difficulties, I felt I had no choice but to leave school.

I stayed out of school for over a year doing very little learning and seeing virtually nobody. Despite this, during this time my mum and I identified PDA as something I might have, and I later got diagnosed.

I learnt a lot about PDA that year and felt it explained a lot of things about me and my behaviour.

I refused to get any support from therapists or professionals since I found it very demanding attending and answering their questions in the past.

Eventually in the middle of year 9, I decided I was ready to go back to a school. I felt it was the best and easiest way to get my GCSEs since I briefly tried learning at home, but it didn't work out for me.

We found a different school with smaller class sizes, and we decided it would be less stressful. Obviously, I had missed a lot of the curriculum since I missed a lot of school which made things even more difficult since I was behind others.

Despite my hopes, this school was not much different to my old one and throughout year 9 and 10 I had some more nasty experiences driven by anxiety and constant need to mask.

I also struggled with friendships more than ever since I hadn't socialised in a while and had forgotten how it worked. I went through several different friendship groups and met some nice people along the way.

I also decided to try and tell some of my close friends about my PDA which is something I'd never done before, so I was extremely nervous. Some of them understood better than others but I got a couple of responses that shocked me saying I was making up 'excuses' and 'other people have it harder than you'.

At the same time though, there were 1 or 2 who really went above and beyond my expectations and researched more about PDA and really listened to me properly. (You know who you are if you are listening to this now, thank you)!

Towards the end of year 10, after being a part of multiple different friendship groups throughout year 10, I decided socialising was causing too much stress and I decided to isolate myself from my peers.

I sat by myself at lunch and break times and really began to gradually lower my mask, which felt really weird, but it made me less stressed at first. However, of course, since I was acting so differently and nobody was used to seeing this side of me, people were confused, and I heard all sorts of stupid rumours circulating about me. Therefore, I quickly decided that lowering my mask was not a practical solution as I'm sure it was only a matter of time before other students began making my life even worse through mocking me and making fun of me.

I hope this explains why it is so terrifying for PDAers to lower their masks and unfortunately, I wouldn't personally feel comfortable dropping my mask at school. This further emphasises how demanding masking is and how much I rely on it to appear 'normal'.

On the other hand, there are definitely some good reasons for PDAers to try and lower their mask at places like school. For example, masking really does take a toll on my mental health. Therefore, if you find a way to drop your mask that works for you at a place like school, I think you should give it a try.

In this overview of my experience of school I explained briefly what happened but now I would like to explore why I think many people with PDA struggle with school to this extent and some possible solutions to make it easier.

Firstly, I would like to address the socialising side of school. Many people with PDA will mask during socialisation without even thinking about it. It's just an instinct and I certainly cannot help it.

Anyway, masking is extremely draining, and since in school you are surrounded by so many pupils and teachers who some of which are unknown and judgemental, this can make it very uncomfortable and a further demand to mask.

Masking plays a huge part in life for many PDAers, and it is also a huge issue in school. Especially when undiagnosed people with PDA will not even know why they are doing it (like me in primary school for example).

If you would like to learn further about my thoughts on masking, I have done an audio so you can listen to that on the PDA Society website if you are interested: <https://www.pdasociety.org.uk/resources/pda-masking-with-james>

Another thing I find difficult about school as a PDAer is the anticipatory anxiety. Anticipatory anxiety is the anxiety felt before an event. For example, I often find anticipatory anxiety around demands extremely stressful.

I get stressed about school the next day, the night before I go. This is not good for my mental health and means I don't have the time to relax and am instead having intrusive thoughts about what COULD happen. Also, a lot of the time, it never even happens, so I could simply ruin an evening for myself which is understandably quite frustrating.

An aspect of PDA is that people with PDA get extreme anxiety about everyday demands. Therefore, it may not take a particularly stressful event to stress somebody with PDA.

A person with PDA may just become overwhelmed by a few things whether they are demands, sensory issues, social problems or teachers putting too much pressure on us.

When I am in a class I do not like, I am already stressed to an extent due to the anticipatory anxiety. This means, I can be tipped over the edge by the smallest of things like getting some homework set. However, when I say 'tipped over the edge' it still may not be noticeable since, as I have said, many PDAers masks are so believable.

When other autistic people are 'tipped over the edge' they may have a meltdown right there. It is different for me. I continue to mask through these stresses and take the stress to later, like when I am at home from school in a safe place for example. This does not mean we aren't feeling as bad as other autistic people when they are having a meltdown. It simply means our brain works in a different way and holds onto the stress while keeping the mask up as it was before.

A question I have got from a lot of different people is 'why do people with PDA find demands difficult?'. I struggle to answer this question because it's a complex answer and I'm not actually too sure of myself.

I feel the reason FUTURE demands trigger me and many others with PDA is because they force our brains to think about completing the demand. However, PDA forces us into OVERTHINKING which is where the anxiety comes in.

Too much overthinking about scenarios before they have even happened leads to our brains taking what we already know and filling in the gaps. This means we have a false idea of the future event we are worrying about due to our brain automatically filling in the gaps and most of these worries won't even end up happening. Therefore, we are fuelled with anxiety about overthinking about a future demand.

So, perhaps it is not the demand itself we struggle with in this case, just the overthinking about the demand. Of course, it is caused directly by the demand which is probably the reason it still comes under the title 'demand avoidance'.

The reason I think this is because when I get a demand such as doing some homework, I find that the quicker I get on with it, the less stressful it actually becomes. For example, if I get some homework on a Monday and can't do it that day because I already have a club to attend, during the club, all I will be thinking about is completing the demand instead of actually enjoying myself at the club.

After the club it may be my bedtime, so I end up worrying about the demand whilst falling asleep. As a consequence, I can't sleep and have stomach problems. Therefore, I'm already in an overly tired, anxious mood before even going into school the next day.

This is just an idea I have about a certain type of demand avoidance, which I call anticipatory demand avoidance. I understand my opinions on why future demands are difficult may be controversial, but I really do think it makes sense and I'd love to hear whether people can relate.

Now I would like to explain my views on near-future demand avoidance. For example, the demand to brush my teeth. This is something I am awful at since it is a demand AND I have some sensory problems with the toothpaste. So, if my mum reminds me to brush my teeth, I immediately feel I am not in control because I now MUST brush my teeth.

Now, I would be thinking of excuses and strategies to avoid this demand. For example, I may say 'I am about to have a snack, I'll have to do it later', or do something 'silly' like walking past the bathroom to jump on my bed.

When I was younger and my parents did not know about my PDA, they may have got annoyed at this 'strange behaviour' and told me firmly to brush my teeth. Little did they know this only made me less likely to brush my teeth and more likely to throw a meltdown.

This is why my parents having a good understanding of PDA is really helpful and makes my behaviour better these days, preventing meltdowns and generally making me happier.

In this scenario what I would do is just walk off and take the pressure off a PDAer completely. This works very effectively for me.

In my opinion, most teachers have high expectations to try and get the best out of their pupils. This is a natural thing for teachers to do since they really do want the best for their pupils.

As a result of their high expectations, they can unintentionally become demanding in the tone of their voice or choice of words. This is going to get the worst possible outcome for people with PDA since they work far better and more efficiently when they do not feel demanded. For example, when I am about to do some particularly demanding homework, I can end up simply sitting at my desk mentally preparing myself to start the work, usually for at least 30 minutes.

This may sound ridiculous, and I don't know if this is common among other PDAers, but it is a difficult habit to break. Also, during this time I am too stressed to think clearly so I can't start the work until I have calmed myself. Furthermore, I know I have to do the work at some point, so I always want to get it out of the way. This leads to this extremely dull and painful cycle of waiting to try and complete the demand.

Another example of stress for children at school with PDA is the changes aspect.

There are a lot of changes throughout life, but I find it particularly challenging going through everyday changes. This includes going from one lesson to another or going from home to school or vice versa.

Also, another example is since it was the end of term for me recently, we had a lot of 'special treats' like watching a film during lessons for example. This change is particularly frustrating for me because it is completely unnecessary because we might as well be relaxing at home since we are learning virtually nothing.

There are more demands involved in watching a movie at school than you think too. I have to sit still, be quiet, keep my mask up since people will still talk, and I have to pretend I'm enjoying myself to blend in.

There are also changes like going from holiday to school term and weekend to weekday since my daily activities are going to vary and autistic people find this difficult.

A type of demand that a lot of people may overlook is demands from our body. This may sound silly but when many people with PDA are hungry, thirsty or need the toilet, they can take this as a demand from their body.

This is the reason I often struggle to drink enough, since I always avoid the demand. Obviously, drinking water is essential and it was a real problem for me. Occasionally, still nowadays, when I know I am thirsty but have processed it as a demand, I ask a member of my family if they would get me a drink.

This could sound very lazy to some people that know very little about PDA, but it still can be processed as a demand to many people with PDA.

Also, knowing I am able to ask my family to get me a drink can reassure me it is not a demand. This means, if I am reassured it is not a demand, it is no longer as much of a problem and this is why I usually am able to get myself drinks without problems anymore.

Since school takes up 6 hours every day, it also provides more pressure to do other home demands like brushing teeth, showering, eating, homework, changing etc. This is because we have less time to work with so we will feel more under pressure to do these tasks.

Moreover, although my mum takes me in and collects me from school in the car, I can understand why some people with PDA can find getting in and out of school stressful. This is because they will still have to mask on public transports and there are extended demands linked with the transport.

These can include stress about tickets, feelings of uncertainty about when the public transport will arrive and more. There will also be many changes in bus or train timetables. There could also be delays, breakdowns etc.

Another stress about going to school is the organisation side of things.

In primary school and year 7 I had to pack my bag every night before school. This stressed me for a number of reasons. For example, it gave my brain an opportunity to overthink since I am forced to think about school the next day. I also fear forgetting my books and equipment because this would lead to more stressful changes, for example getting told off by the teacher or having to use unfamiliar equipment.

Mostly I feel this is just another daily demand we need to get on with. I even found packing my bag so stressful, now my mum packs it for me. Also, although I know she does a very thorough check of it, I always feel anxious she will forget something, so I always check it afterwards.

This is yet another example of one of the reasons school is stressful for PDAers. There is not really one individual reason school is stressful for PDAers. I find it's more the combination of many little things.

The advice I would give to teachers with pupils with PDA would be to try and make their work less demanding through your choice of words and perhaps make homework optional.

Another way to make homework less demanding is to not overset it. Oversetting homework will not benefit any pupils since they will not be learning with the stress of getting the homework done. Therefore, I feel it is completely counter intuitive.

I also feel a small thing teachers could do to help pupils with PDA like myself, is giving them a space to go when they are feeling overwhelmed. This will reassure

them they don't have to stay in stressful situations and can escape to a safe place at any given time.

Teachers should try and be flexible with their work expectations and perhaps give the pupil some choices, so they are more in control of their own learning.

Over my time in school, I have come up with a few general coping strategies that I have used to survive school when feeling stressed. I'd be delighted if you found any of these useful but remember they may not work for you since everybody is different and everyone has their own strategies.

An example of one of my strategies is trying to move around to take your mind off demands. Obviously when in class you may feel a little awkward getting up and doing a dance. However, it's easy and subtle enough to just move your legs a bit under the table and try to concentrate on them for a while.

Another example is if there is a clock in your classroom, just tap along gently to the seconds. This helps distract my mind and calm my breathing.

Another tip that can be used for home or school, is when you have a demand to do, just count down in your head from five before your brain can oppose. This avoids overthinking and anticipatory anxiety and is probably what has got me through most of secondary school.

This has been a difficult piece to write because in my brain, everything about school seems to merge into one big demand which is going to school every day.

It is difficult for people like me to talk to trusted people like parents since I believe something about my PDA brain merges demands together to the point where it's hard to identify the individual issues. If that makes sense anyway!

Thank you so much for listening and I hope you have been able to decode some of my dodgy English and learn something about why life at school is difficult for PDAers and sorry if I went off on tangents a little!

Lastly, I would like to thank everybody who left me such positive and encouraging comments on my last audio. I read each and every one of them and am delighted you all found my audio useful!

If you have any comments about any of the topics I have spoken about today, please, I'd love to hear them so feel free to give any of your own thoughts too (preferably on Instagram!)

Thank you so much again and goodbye.