



Individuals with PDA can appear to be very sociable and confident, but learn quickly how to move away from perceived demands

PDA in school

Tigger Pritchard outlines how to support children with pathological demand avoidance (PDA)

Back in the 1980s, developmental psychologist Elizabeth Newson realised that some children being referred for a diagnosis of ASD were presenting very differently from those with classic traits. Nor did they fit the definition of ‘atypical autism’ or ‘pervasive developmental disorder not otherwise specified’ as classified by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). As a result, she developed her theory of pathological demand avoidance (PDA).

Much has happened since then. In 2007, the National Autistic Society (NAS) recognised PDA as an associated condition and included information on its website. In 2015, with ASD now seen as synonymous with pervasive developmental disorder, the NAS made it clear that PDA was a part of the autism spectrum. Since 2011, it has held regular conferences on the topic. A group of parents set up the PDA Contact Group back in 1997 which became the PDA Society in 2014. Meanwhile, several books have been published on the topic and many online support groups have been started on social media.

More is also being understood about the autism spectrum and this has helped

to show that other issues needed to be taken into account. As yet, there is comparatively little research around PDA, although this is changing. In diagnostic terms, the condition is very new; it does not yet feature in the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-5) or the International Classification of Diseases (ICD-10). However, more and more parents and professionals are beginning to see the need for recognising the PDA profile in ASD.

What is PDA?

Some people believe that PDA is a result of bad parenting, or too much or too little discipline, a fad or related to diet. It is none of these. PDA is a lifelong condition and presents 50/50 in males and females.

‘Pathological’ means that actions that might appear insubordinate are completely out of the control of the individual; they are not being wilful or rude.

Nor can it be regarded as a power game, or being naughty. For the person concerned, a request (demand) might produce a level of anxiety that is beyond anything the rest of us can even begin to imagine.

‘Demand’ means any demand: direct, indirect, implied or consequence. Even internal demands such as ‘I ought to’ are

included.

‘Avoidance’ means that the individual will not be able to do what is asked of them. It is not that they do not want to; they cannot.

To give people a glimpse into what it might be like, during training sessions for school staff I sometimes ask everyone to stand and then announce that I will pick on them one by one to answer a maths question verbally. Although I don’t actually carry this through, I see a sudden increase in anxiety in many people’s faces. In the discussion period afterwards, teachers and TAs alike talk about this rise in anxiety and how fast and uncontrollable it was.

I go on to explain that many everyday aspects of communication and interaction can be highly anxiety laden for individuals with PDA. Even something as non-threatening as ‘How are you?’, ‘Would you like a drink?’, ‘What shall we do today?’ or praise can be difficult for a person with the condition.

The characteristics

Pupils with PDA may:

- obsessively resist ordinary demands
- use social strategies to avoid demands – e.g. distracting and giving excuses
- appear sociable but lack understanding (often recognised by parents early on)
- appear to be listening and even taking part but may be switched off
- have excessive mood swings and impulsivity
- be comfortable (sometimes in an extreme way) with role play and pretending
- try to dominate or control social interactions, especially when they feel anxious
- have behavioural difficulties
- display obsessive behaviour, often focused on people rather than things
- have language delay, possibly as a result of passivity, but there is often a good degree of catch up (although there is less emphasis on this these days as it is not a common characteristic).

(Phil Christie and Margaret Duncan, NAS, 2013.)

Reactions to a demand

Demands may be perceived or actual; the person will resist ordinary demands of life. It is not so much the activity they are refusing, but that someone else is asking them to do it, or even that they themselves really want to do it. They may react by:

- refusing
- incapacitating themselves

- distracting or changing the subject
- ignoring demands or giving a delaying response
- arguing or suggesting alternatives
- mimicking, making noises or drowning out demands
- withdrawing into a fantasy world
- walking away
- becoming aggressive or having a panic attack or meltdown
- making excuses.

Taking control

Typical responses you may hear include the following.

- ‘I can’t possibly do that now.’
- ‘Your necklace is very beautiful; where did it come from?’
- ‘My legs will no longer listen to my brain, they are like stone!’
- ‘But I have to finish this first.’
- ‘Did you know about the Human Rights Act in relation to work?’

Individuals with PDA can appear to be very sociable and confident, but they use their grasp of social skills to ‘deskill’ or ‘depower’ a situation. For example, some individuals I have worked with learn quickly how to catch me off guard and are able to rapidly and very cleverly take control and move away from perceived demands. Here are some characteristic examples that have caught me out recently. ‘Did you sleep OK last night?’ ‘Is that still the watch with a compass? It’s so cool. What else does it do?’ ‘Have you seen the weather forecast today? What do you think?’

While there are individuals with PDA who have learning difficulties, individuals are often very intelligent and extremely adept at redirecting demands.

ASD and PDA

Although PDA is on the ASD spectrum (and is also a dimensional condition, so individuals vary) there are some important differences between those with PDA and those with typical autism and Asperger syndrome. Pupils with other forms of ASD:

- find eye contact difficult
- have difficulty with social interactions
- may respond well to rewards and behaviour plans
- can struggle to show empathy and imagination
- find reciprocal conversations difficult
- do not pathologically avoid demands.

Pupils with a PDA profile:

- have better eye contact
- learn to socialise, but will still have

- some underlying difficulties
- like spontaneity and dislike routine
- find rewards and rigid behaviour plans difficult
- are imaginative
- show empathy
- have good conversational skills.

PDA and ODD

PDA is sometimes confused with oppositional defiant disorder (ODD). However, in a small study supervised by Elizabeth Newson that compared children with both conditions, researchers found that the children with PDA used a wider range of avoidance strategies, including social manipulation. In contrast, children with ODD tended to refuse and be oppositional but did not use the range of avoidance strategies. Pupils with PDA are autistic and:

- have difficulties with social interactions, communication and obsessions
- go to extreme levels to avoid demands
- consider themselves adults, even when they are still very much children
- seem to experience higher levels of stress.

Pupils with ODD:

- do not have significant issues with social interactions, communication and obsessions
- do not show the same level of demand avoidance

- reject demands from authority, not the demand itself
- respond to rewards.

Support strategies

Although PDA is an autism spectrum disorder, the support strategies often used with others on the spectrum may not work with pupils with PDA. If anything, structure and routine are perceived as yet more demands. A starting point is to understand that classroom settings have many demands, all of which serve to raise the person’s level of anxiety.

Two dials

One technique that can help school staff manage a situation is to imagine they have two dials marked 0-10: one showing the pupil’s level of anxiety, the other showing the adult’s level of demands. The adult’s dial should be moving constantly in the opposite direction to the child’s. As the child’s stress levels rise, so the adult’s demands will reduce to zero. As the child becomes comfortable, so the adult can gradually increase the level of their demands. In other words, as a teacher you must be prepared to take an extremely fluid, personalised and individual approach throughout the day.

Find out key information

Every person with PDA is different and

Case study

Isaac explains how PDA affects his life

I am autistic first.

I can’t touch very soft things, creams and gels, and I’m very selective with my meals and only eat the same foods over again. I have to be fiddling with something all the time. I often talk very quickly and too loudly and feel out of step socially. My special interests are about stories and characters, and I am extremely passionate about fairness and social justice. Growing up was hard – I didn’t have much sense of ‘self’ and wasn’t resilient. But I am now proud to be a nerd, and trans, and autistic.

But my autism doesn’t always present as typical.

I generally have little trouble making eye contact and am good with language. In fact, I love talking to people (although I can struggle with peers). No one spotted I had autism until I was 13, when I dropped out of school.

My mood can change almost instantly from bubbling with excitement to lethargic and low. But my biggest issue is my constant, insurmountable anxiety, which prevents me from doing pretty much everything. I panic when asked to do anything (from clearing away my plate to going on a trip), although I also feel the same panic when no one has asked me but I think I *should* do those things. The more I want to do something the less able I am do it.

Everything in my life is affected – I struggle immensely with basics like washing, getting dressed and even eating (which, as you can imagine, can cause some health issues). I try my best but it isn’t the sort of anxiety that you can push through and things like routines or simple steps to follow just make it harder. It is literally paralysing and the only way around it is to try and out-trick my brain and keep things really flexible. I am lucky to have a lot of understanding people surrounding me who really ‘get’ PDA, and that makes life so much easier.

Isaac is 18 and lives in a residential setting in a special school. He set up That Autism Feel, a resource on tumblr.com



Priority rating chart		
Prioritising behaviour – how important is it that a pupil does the following?	Priority rating	Comments
Sits on a chair during classroom teaching sessions.	3	More important to stay in the designated area of class to minimise disruption to others.
Keeps shoes on in school.	3	Having shoes on to go outdoors will be a requirement, but doesn't have to join in playtime.
Attends assembly.	3	Not important – in fact, can we use this time for personal tutorials or additional PSHE work?
Does not damage property.	1	Non-negotiable. He will be prevented from doing this.
Uses pupil toilets at school.	3	More important that he uses a toilet in school – will nominate a particular toilet for his use.
Does not hurt other people (adults or children).	1	Non-negotiable. He will be prevented from doing this.

From *Understanding Pathological Demand Avoidance Syndrome in Children* – see *Find out more* below

the relationship you have with them is of paramount importance. Find out as much as you can from parents/carers and keep lines of communication open. If parents are hard to reach, you will need to find a way to work with them, which may involve visiting them at home. Use the table below to get a better understanding of how best to support the pupil.

Minimise ground rules

Some teaching professionals put a wide variety of ground rules in place, but if there are too many, it becomes difficult for pupils with PDA to understand and process them, and the rules are consequently seen as yet another list of demands. Remember, it is not 'I will not' but 'I cannot'.

Coordinate approaches

Staff training in PDA and support is essential. Misunderstandings sometimes arise when different staff use different approaches, so everyone needs to work as a team.

What are your priorities?

The key question to ask yourself is: 'What is really important in a given situation?'

It may be that wearing shoes in class is not important, but not running into the road is. So you will want to concentrate on ways to support not running into the road and may have to learn to live with shoes off in the classroom. It may help to work out the school's priorities in advance using the priority rating chart (above).

Meanwhile, the less personal the demand, the more likely it is to work. Strategies that may help include playing games, using characters, the child's favourite Pokémon or action character, or drama or fantasy. Alternatively try offering choices. For example, you may find yourself saying some of the following.

- Which song will we play at the end of the lesson?
- You choose. I have no idea.
- I wish I knew how to do this.
- I don't know what to do first.
- Look at all of these things on the floor. Where am I going to put them?
- I'm really good at doing this. No one can beat me!
- Wow, look at this!

Unfortunately, a strategy may work one day but not the next, so you need to adjust your expectations constantly. Meanwhile,

be careful with praise as this might be perceived as an implied demand – the expectation that they will be able to do the same thing just as well every time, which is unachievable for people with PDA.

Meltdowns

Individuals with PDA will have meltdowns – demands are everywhere. Consequently, the behaviour they may present can be very challenging. Remember that during a meltdown, they will be anxious and upset in a way you cannot comprehend, and their behaviour is beyond their control. Try to be reassuring, supportive and understanding.

The important thing is to be flexible. While it may be strange working outside the usual rules, it can often be fun. The aim is to be as non-confrontational as possible. Remember, it is not about showing them who is in charge but about reducing the pupil's stress levels so that they can engage and learn.

Top tips

- Minimise anxiety.
- Ask yourself if you have to stick to the timetable.
- Think about free time; demands are everywhere.
- Use role play.
- Think out of the box.



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FIND OUT MORE

- **National Autistic Society:** www.autism.org.uk
- **PDA Society:** www.pdasociety.org.uk
- **The Cambian Group** specialises in behavioural health services: www.cambianguroup.com
- **The PDA Resource** has lots of useful links: www.thepdaresource.com
- **Understanding Pathological Demand Avoidance Syndrome in Children: A guide for parents, teachers and other professionals** by Phil Christie, Margaret Duncan, Ruth Fidler and Zara Healy. Published by Jessica Kingsley Publishers. ISBN 9781849050746
- **The Explosive Child: A new approach for understanding and parenting easily frustrated, chronically inflexible children** by Ros W Greene PhD. Published by Harper Paperbacks. ISBN 9780062270450
- **Pathological Demand Avoidance Syndrome: My daughter is not naughty** by Jane Alison Sherwin. Published by Jessica Kingsley Publishers. ISBN 9781849056144

What PDA means for me		
I have pathological demand avoidance. It means my brain is wired differently from most people's. There are some things that I can do better than most people as a result, and I find other things very difficult. I will get very anxious much of the time and am quite good at covering it up sometimes, but it makes it very difficult for me. I hope this sheet will help you know what will help me.		
PDA trait	What it means for me	What would help
I struggle when I want to do something for myself – I often find I can't.	I get anxious when I start to do everyday things like thinking about showering, and even doing something nice. For example, a trip to the cinema is hard.	If people encourage me, it makes it worse, but with time and space and others around me doing the same things, I think it will get easier. (At the moment I need Mum to do most things for me – I hope to be able to do more for myself again.)

From the PDA Society by Sally Russell

