What is PDA?

A guide to the Pathological Demand Avoidance profile of autism
What is PDA?

Pathological Demand Avoidance (PDA) is widely understood to be a profile on the autism spectrum, involving the avoidance of everyday demands and the use of ‘social’ strategies as part of this avoidance. 

Whilst autism is a well-recognized term, our understanding of the full breadth and complexity of the autism spectrum is still evolving.

The National Autistic Society explains autism as “a lifelong disability which affects how people communicate and interact with the world”. Many autistic advocates embrace the social model of disability and view a range of neurological differences as being part of a natural human variation (neurodiversity).

A PDA profile of autism means that individuals share autistic characteristics ...

- currently defined as “persistent difficulties with social communication and social interaction” and “restricted and repetitive patterns of behaviour, activities or interests”
- and often including a different sensory experience in relation to sight, smell, taste, touch, hearing, and internal senses such as hunger or thirst ...

and also have many of the ‘key features’ of a PDA profile:

- resisting and avoiding the ordinary demands of life
- using ‘social’ strategies as part of the avoidance (see “How are demands avoided?” on page 7)
- appearing sociable, but lacking some understanding – individuals may appear more sociably ‘able’ than one might expect (with, for instance, more ‘conventional’ use of eye contact or conversational skills but this may mask underlying differences/difficulties in social interaction and communication
- experiencing intense emotions and mood swings
- being comfortable in role play, pretence and fantasy – sometimes to an extreme extent
- focusing intently, often on other people – with PDA, “repetitive or restrictive interests” are often social in nature, relating to real or fictional people
- a need for control which is often anxiety related
- a tendency not to respond to conventional approaches in parenting, teaching or support.
How PDA can feel

I like to describe the experience of being under a demand as similar to having claustrophobia. The anxiety keeps rising steadily until it becomes a non-negotiable, panic-driven need to flee from the source of the demand - Tony

Demand avoidance makes it sound like I’m avoiding things on purpose, but I literally have no choice in it whatsoever. So I prefer to call it demand anxiety - Tally (from the book Can You See Me?)

It’s like you’re gaming and you have the main controller, and then sometimes someone yanks that controller away from you and you lose control and feel panicky - Mollie

I feel most anxious when I’m pressed to do something I feel I can’t do, but when people around me don’t understand what I mean when I say “I can’t do that”. I know how to do things, and I can do them sometimes, but most of the time I just can’t. It starts with avoidance but if someone insists I’ll go straight to panic. I go from being sort of OK to crashing down a hill. It’s the most frustrating thing to have the functional capacity to understand what’s happening but the functional ability just isn’t there. It’s the worst form of self-sabotage – Isaac

Demand avoidance is everything. After a day of social interaction I might need a week of recovery. My anxiety bucket doesn’t empty naturally. I never want to get to the point where it’s full as then my cognitive ability becomes too impaired and I can’t cope - Julia

Positive PDA

It’s always so important to focus on strengths and positive qualities – these are some of the words parents most commonly use when asked to positively describe their PDA children.

One size doesn’t fit all

Autism is ‘dimensional’ - involving a complex and overlapping pattern of strengths, differences and challenges.

Presentations can change over time, or vary depending on an individual’s overall physical health and mental wellbeing (including any co-occurring conditions), or depending on the environment they’re in (not just the physical setting but also interpersonal relationships).

A PDA profile of autism can be ‘extrovert’ where demand avoidance is quite overt, or it may be ‘introvert’ where demands may be resisted more quietly and difficulties are masked.

So, helpful approaches will need to be tailored to each individual.

*published by Scholastic
Demands in PDA are many and cumulative.

‘Demand avoidance’ involves not being able to do certain things at certain times, either for yourself or others, and also refers to the things we do in order to avoid demands. It’s a natural human trait – avoiding demands is something we all do to different degrees and for different reasons.

When demand avoidance is more significant there can be many possible reasons for this – it could be situational; relate to physical or mental health; or relate to a developmental or personality condition – so a PDA profile isn’t always the best explanation.

Pathological demand avoidance is all-encompassing and has some unique aspects:

- Many everyday demands are avoided simply because they’re demands. Some people explain that it’s the expectation (from someone else or yourself) which leads to a feeling of a lack of control, then anxiety increases and panic can set in.

- In addition, there can be an ‘irrational quality’ to the avoidance – for instance, a seemingly dramatic reaction to a tiny request, or the feeling of hunger inexplicably stopping someone from being able to eat.

- The avoidance can vary, depending on an individual’s capacity for demands at any one time, their level of anxiety, overall health/wellbeing or environment (people, places and things).

PDA demand avoidance isn’t a choice and is lifelong – it’s seen in infants and remains part of the experience into old age. With understanding, helpful approaches from others (page 9) and finding self-help and coping strategies (page 11), PDA demand avoidance can become more manageable.

It can be helpful to think about some of the different ‘types’ of demands including:

- **Direct requests or questions from others** - such as ‘put your shoes on’, ‘you need to pay this bill’ or ‘would you like a drink?’

- **Indirect demands** - such as praise (which can lead to anxiety over future expectations rather than the intended positive reinforcement) ... or time (an additional demand on top of the demand itself) ... or uncertainty (not knowing or not being in control of what’s happening can trigger anxiety).

- **Demands within demands** - the smaller implied demands within larger demands (e.g. within the demand of going to the cinema are the demands of remaining seated, responding appropriately, sitting next to others you don’t know, being quiet etc. etc.)

- **The ‘I ought to’ feelings of daily life** - such as getting up, washing, eating, learning, sleeping.

- **Our own internal demands** - such as thirst or needing the bathroom as well as thoughts and wishes.

- **Things we want to do** - like hobbies, seeing friends or special occasions ... not just things we might not want to do like homework or housework.
How are demands avoided?

With PDA, people may refuse, withdraw, shutdown or escape in order to avoid things, though more often other ‘social’ approaches are tried first – there’s usually a hierarchy of avoidance approaches (although escalation can be very rapid, especially if pushed).

Initial avoidance approaches might include distraction (changing the subject), engaging in interesting conversation, using delaying tactics, excusing yourself (giving explanations as to why you can’t comply), incapacitating yourself (saying ‘my legs don’t work’) or withdrawing into role play or fantasy.

If these approaches don’t enable the demand to be avoided – or aren’t noticed or acted on by others – panic may rise, resulting in a fight, flight or freeze anxiety response. Meltdowns in PDA are best understood as being like panic attacks.

Understanding this hierarchy of avoidance approaches is key when thinking about effective ways to help.

Identifying PDA

Identifying a PDA profile can be difficult and it’s not uncommon for a PDA presentation to be:

- **missed** - because sometimes the underlying autism may be less apparent at first; or because an individual’s presentation may be quite different to what some people think autism ‘looks like’; or because individuals may ‘mask’ their differences (masking means hiding or holding in your differences/difficulties in certain environments or with certain people)

- **misunderstood** - often because the focus is on “behaviours” and not underlying causes; or because other factors are thought to be the cause (sadly, with children, parents being blamed can be a common problem). However, it’s also important to remember that PDA isn’t the only explanation for demand avoidance

- **misdiagnosed** – because there are some overlaps and connections in clinical ‘features’ between PDA and other presentations, PDA is sometimes misdiagnosed as Oppositional Defiant Disorder (ODD), Conduct Disorder (CD), Reactive Attachment Disorder (RAD), Personality Disorders or Developmental Trauma.

Whilst there is currently a range of clinical and academic viewpoints about the PDA profile of autism, clinicians who assess for and use terminology around PDA (such as ‘ASD with demand avoidant traits’ or ‘Autism with a PDA profile’) do so within current medical guidance, because assessments should use a ‘dimensional approach’ to identify strengths and needs and to signpost helpful approaches.
Conventional approaches, including those often recommended for autism (such as routine, structure and predictability), are often ineffective and even counter-productive for a PDA profile.

In place of firm boundaries and the use of rewards, consequences and praise, PDA adults and children respond better to a person-centred, holistic approach based on trust, negotiation, collaboration, flexibility and careful use of language.

We chose the panda as our ambassador to convey this concept, as giant pandas also need a tailored approach in order to thrive. Pandas also need an integrated approach to their care – with PDA this means individuals, families, support networks and multi-agency professionals needing to work together.

**P A N D A** is also a useful summary of helpful approaches for PDA.

**Helpful approaches**

<table>
<thead>
<tr>
<th>Pick battles</th>
<th>Anxiety management</th>
<th>Adaptation</th>
<th>Disguise &amp; manage demands</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>minimise rules</em></td>
<td><em>use low arousal approach</em></td>
<td><em>try humour, distraction, novelty and role play</em></td>
<td><em>word requests indirectly</em></td>
</tr>
<tr>
<td><em>enable some choice and control</em></td>
<td><em>reduce uncertainty</em></td>
<td><em>be flexible</em></td>
<td><em>constantly monitor tolerance for demands and match demands accordingly</em></td>
</tr>
<tr>
<td><em>explain reasons</em></td>
<td><em>recognise underlying anxiety and social/sensory challenges</em></td>
<td><em>have a Plan B</em></td>
<td><em>doing things together helps</em></td>
</tr>
<tr>
<td><em>accept that some things can’t be done</em></td>
<td><em>think and plan ahead</em></td>
<td><em>allow plenty of time</em></td>
<td><em>doing things together helps</em></td>
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There’s lots more detail, information and resources about helpful approaches for PDA on our website.
These suggestions for self-help, coping strategies and therapies were assembled from a variety of first-hand accounts from PDA adults. There’s more detail, information and resources on our website.

- Recognise **what demands are and how you avoid them**, be **aware of your triggers**
- **Accept yourself** – understand how you may be ‘masking’ and find your tribe
- Find ways to **manage, reduce and disguise demands** – have demand-free time
- **Inform others** and ask for **accommodations** – explore different ways of working
- Consider person-centred **counselling, mindfulness or meditation**

My choice of career is quite specialist ... working within a niche environment means there aren’t the usual financial pressures and deadlines. Working in a company that practises a person-centred ethos means I’m given space to think and process information at my own pace. Along with adjustments at work, over the years I’ve developed many coping strategies to help deal with life’s challenges. I count myself as one of the lucky ones – Tim

Every single thing I do involves battling demand avoidance and I can only do so much ... awareness of my limitations has given me the wisdom and confidence to set personal goals that I can keep - Sally*

It’s easier to get things done if we can laugh about it, so if we can make things into a game then we do. If I can distract myself with debates, music and made-up songs/rhyming games, I’m able to do a job on autopilot - Becca B*

I’ve found that by giving myself an ‘out’ then it is much easier to meet demands, because I know I can change my mind whenever I want - Riko*

I have my partner to thank for this phrase: “A demand shared is a demand halved”. She’ll involve me in cooking, washing, cleaning ... which I know makes it more manageable for her. So, share the demand and then it becomes less! - Paul (Partner of PDA adult)

*extracts from PDA by PDAers, Jessica Kingsley Publishers
All research points to early understanding of strengths and needs, together with appropriate support, being key to positive long term outcomes.

Some PDA adults thrive in employment, particularly where they have sufficient control and a deep interest in the activity. Others may move regularly from one job to another, by choice or necessity, whilst others find they can’t function in a work environment. Some need significant support from loved ones and/or the care system; others don’t require support.

Children and young people may struggle with the school environment, and school ‘refusal’ is common with PDA. Sometimes schools are able to make sufficient accommodations, specialist placements can be effective and some families find home education works well for their child. In other cases young people are able to ‘mask’ during the school day but may need the time and space to release tension at home.

Many parents find that they need to adapt their parenting style considerably to meet their child’s needs.

Whilst our survey in 2018 highlighted that a PDA profile of autism often results in individuals and families being misunderstood, we look forward to that changing as understanding of PDA and the approaches that help increase.

Benefits of understanding the PDA profile

Researching PDA was a massive ‘lightbulb’ moment! This feeling was cemented when we started trying the suggested approaches … it was nothing short of life-changing: we went from 6-7 incidents a day to 6-7 a week - Zara’s Mum

Before the PDA profile was specified in John’s diagnosis we had no support, 5 school exclusions and a very limited timetable. Afterwards an EHCP assessment was agreed to and he now has the right provision and support - nothing changed just words. I truly believe that without a differentiated diagnosis John would have been lost – to himself, to me and to the world at large - John’s Dad

We thought Zoe may be autistic but her needs were very different to other autistic pupils we had supported in school before, and none of our usual approaches helped. Searching for answers led us to PDA. Seeing Zoe through this lens enabled us to truly understand her and successfully adapt our practices by building trust and embracing a flexible and collaborative approach - Zoe’s teacher

Once I understood about PDA I was better able to articulate my experience of the world to my psychiatrist and take a proactive approach to reducing the daily demands I face. Previously I’d forced myself into mental, financial and physical ruin too many times, just because the world tells me that I “should be able to do it because everybody else can” – Tony

We were increasingly perplexed by the complex presentation of one of our service users and our team’s inability to meet her needs despite our very best efforts. Whilst Sarah doesn’t have a formal diagnosis, following PDA training we were able to devise some unique approaches that have been highly effective. Using these approaches is the difference between Sarah being able to live in her own home and being held in a secure hospital - Sarah’s social care manager

Working with the PDA profile of autism is a completely different way of being, for the individuals and for me, but it works. My biggest challenge and frustration has been the system thinking we should be firm, not negotiate, not give choices, not recognise PDA. This has at times been heart-breaking for the individual and those who support them - Ben’s psychologist
Find out more

There is a wealth of information on our website, including:

- Information for individuals, families and professionals
- Helpful approaches for PDA
- Downloadable resources
- Case studies
- Examples of good practice
- Details on how to get involved

Information is also regularly shared via our social media channels.

Further information about the PDA profile of autism is available on the National Autistic Society and the National Development Team for Inclusion websites.

About the PDA Society

The PDA Society provides information, support and training for people living and working with PDA. We campaign for greater awareness and acceptance and engage with national institutions and local services to see improvements in support for those with a PDA profile of autism.

The PDA Society is led and run by a small volunteer team, all of whom have a direct connection with PDA.

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Charity Number: 1165038

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