



What is PDA?



A guide to the
Pathological Demand Avoidance
profile of autism



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What is PDA?

PDA (Pathological Demand Avoidance) 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-recognised 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 **developmental 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

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 **in addition** 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**
- **appearing 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 **driven by anxiety or an automatic 'threat response'** in the face of demands
- a tendency **not to respond to conventional approaches** in support, parenting or teaching.

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

*published by Scholastic

Positive PDA

It's important not to focus on a list of 'deficits' and forget that we're all individuals ... there are a huge number of strengths and positive qualities that often also accompany PDA.



some of the words parents most commonly used when asked to positively describe their PDA children



some of the qualities PDA adults used to describe themselves, collated from responses in two Facebook groups

One size doesn't fit all

Autism is '**dimensional**' - it involves a complex and overlapping pattern of strengths, differences and challenges that present differently from one individual to another and in the same person at different times (depending on age, or an individual's physical health/mental wellbeing, or their capacity at any given time) or in different environments (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**.

There's no one size fits all, and likewise helpful approaches also need to be **tailored to each individual**.

What are demands?

Demands in PDA are many and cumulative.

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', 'sit here and wait', '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) ... **other people's 'energy'** ... **time** (an additional demand on top of the demand itself) ... **uncertainty** (research from the University of Newcastle found intolerance of uncertainty is a significant factor in PDA, with PDA autistics needing to know *and* feel in control of what's going on).

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, dressing, 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.

What is demand avoidance?

'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. It is sometimes difficult to distinguish underlying causes, but a 'PDA profile' isn't necessarily always the best explanation for extreme demand avoidance.

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.

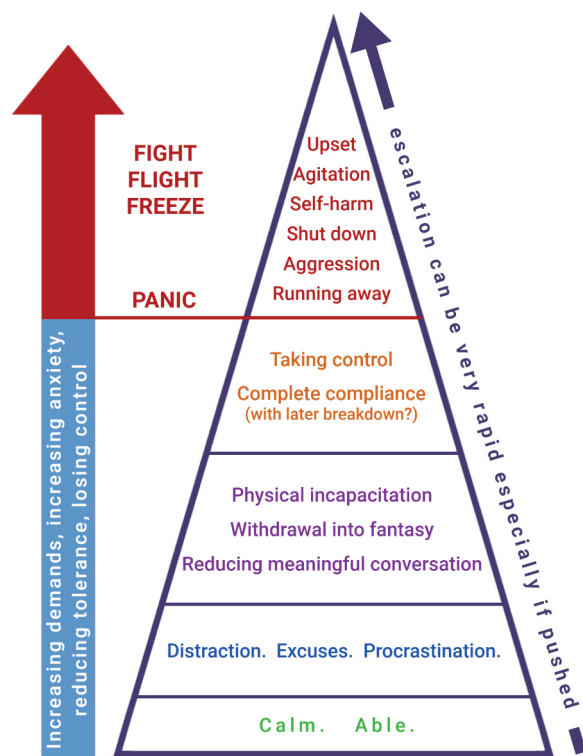
How are demands avoided?

With PDA, people may simply refuse, withdraw, shutdown or escape in order to avoid things, though more often other 'social' approaches are tried first – research from Newcastle University found that 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 or engaging in interesting conversation), **procrastinating**, **excusing yourself** (giving explanations as to why you can't comply), **incapacitating yourself** (saying 'my legs don't work' or 'I'm sorry that would aggravate my arthritis'), **withdrawing into role play or fantasy**, or **reducing meaningful conversation**.

If these approaches don't enable the demand to be avoided – *or aren't noticed or acted on by others* – there may be a rapid escalation as panic sets in and options run out. This isn't a deliberate choice, it's an instinctive flight/fight/freeze/fawn 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 significant 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. Research by Dr Judy Eaton & Kaylee Weaver identified themes in childhood development histories that help to distinguish PDA from some other conditions.

Whilst there is currently a range of clinical and academic viewpoints about PDA, leaders in the field agree that there is a 'recognisable cluster of symptoms' and that this has implications in terms of support. **Assessments should always look carefully at individual strengths and needs**; demand avoidance is listed in NICE guidance and should therefore be identified and highlighted in cases where it's significant. **Under the umbrella diagnosis of autism, a clear signpost to the PDA profile is helpful** because it provides understanding around presentations that may otherwise be perplexing and highlights the need for different approaches when providing support.

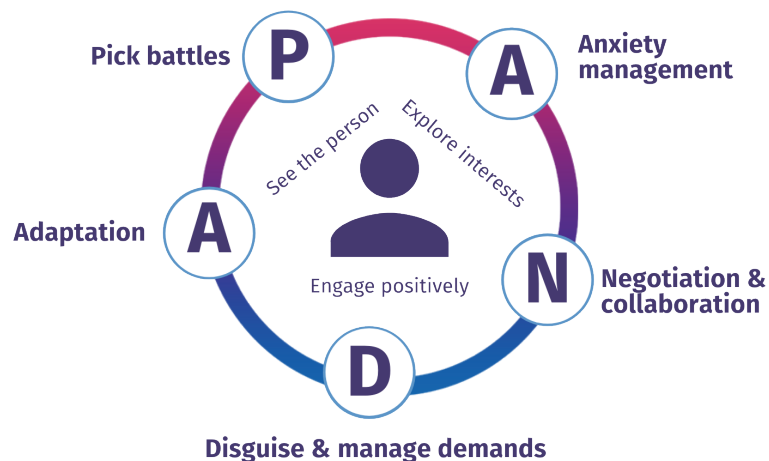


Conventional approaches based on firm boundaries and the use of rewards, consequences and praise, or approaches often recommended for autism (such as routine, structure and predictability), are often ineffective and even counter-productive for a PDA profile.

Low arousal approaches, which keep anxiety to a minimum and provide a sense of control, are good starting points when thinking about what works for PDA. A partnership based on trust, flexibility, collaboration, careful use of language and balancing of demands works best.



The giant panda is our ambassador, since they also need a tailored approach in order to thrive, and the letters **PANDA** also provide a useful summary of helpful approaches ...



PICK BATTLES

P

- minimise rules
- enable some choice and control
- explain reasons
- accept that some things can't be done

ANXIETY MANAGEMENT

A

- use low arousal approach
- reduce uncertainty
- recognise underlying anxiety and social/sensory challenges
- think and plan ahead
- treat meltdowns as panic attacks: support throughout and move on

NEGOTIATION & COLLABORATION

N

- keep calm
- proactively collaborate and negotiate to solve challenges
- fairness and trust are central

DISGUISE & MANAGE DEMANDS

D

- word requests indirectly
- constantly monitor tolerance for demands and match demands accordingly
- doing things together helps

ADAPTATION

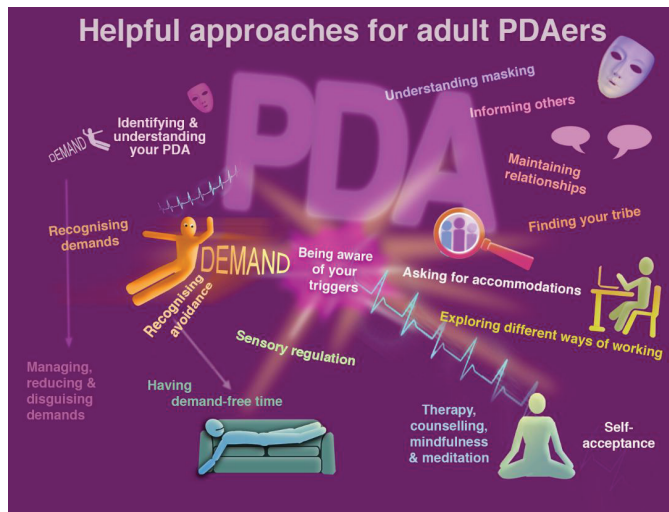
A

- try humour, distraction, novelty and role play
- be flexible
- have a Plan B
- allow plenty of time
- try to balance the amount of "give and take"

There's lots more detail, information and resources about helpful approaches for PDA on our website.

If you feel PDA describes you, these suggestions for self-help, coping strategies and therapies compiled by PDA adults may be useful ... they're explained in detail on our website and include ideas such as

- Recognising **what demands are** and **how you avoid them**, being **aware of your triggers**
- **Accepting yourself** – understanding how you may be **'masking'** and **finding your tribe**
- Finding ways to **manage, reduce and disguise demands** – having **demand-free time**
- **Informing others** and asking for **accommodations** – exploring **different ways of working**
- Considering person-centred **counselling, mindfulness or meditation**



Hopefully both this and the previous pages show that **having 'no demands' isn't the answer** – it's about making adaptations and finding ways to make demands more manageable.

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)

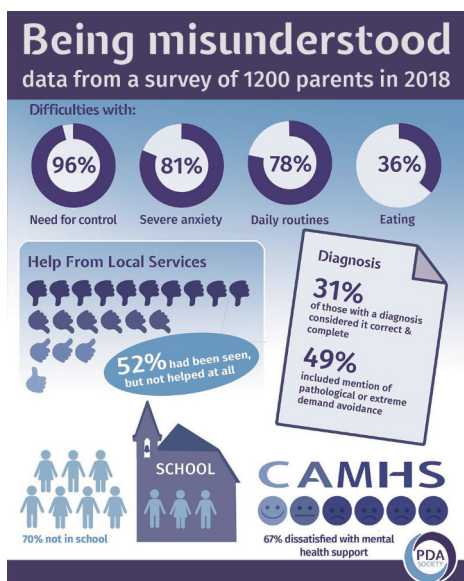


What PDA might mean

All research points to early understanding of strengths and needs, together with appropriate understanding and 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) or find working for themselves more fruitful, whilst others may find they can't function in a work environment. Some may need significant support from loved ones and/or the care system; others require none.

Children and young people may struggle with the school environment, and school avoidance is common with PDA. Sometimes schools are able to make sufficient accommodations, specialist placements can be effective, or 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 time and space to release tension at home.



Most parents find that they need to adapt their parenting style considerably in order 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 this changing as understanding of PDA and the approaches that help, grows.

Understanding PDA can be transformational in terms of outcomes ...

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
- Webinars/videos
- Forthcoming events and training
- Support signposting
- Research background

Information is also regularly shared via our social media channels.

 [thepdasociety](https://www.facebook.com/thepdasociety)

 [@PDASociety](https://twitter.com/PDASociety)

 [pda_society](https://www.instagram.com/pda_society)

 [pda-society](https://www.linkedin.com/company/pda-society)

The PDA Society offers a suite of training options, which we deliver both directly and on behalf of other organisations such as schools, care homes, local authorities, autism charities and support groups.

About the PDA Society

The PDA Society provides information, support and training about PDA for individuals, families and professionals. We aim to increase acceptance and understanding of the PDA profile within the concept of 'dimensionality' in autism and to improve outcomes for individuals and families by focusing everyone involved on 'what helps'.

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

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Charity Number: 1165038



With many thanks to Sally Cat for creating many of the graphics in this booklet and to Julia Daunt for the image on page 5