

NDTI – introductory PDA webinar

Intro slide

Welcome to this introductory webinar about Pathological Demand Avoidance, a profile on the autism spectrum. My name is Vikki Threlfall, I'm a trustee of the PDA Society. This short presentation will provide a quick overview of PDA and signpost resources for further information.

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Autism is a widely recognised term, but understanding the full extent of what the condition means in practice is still very much evolving. Demand avoidance is a natural human trait, but for some it has such a pervasive and extreme impact that it can be described as being pathological.

Individuals with a PDA profile of autism are at particular risk of being misunderstood. This can lead to extremely poor outcomes – 70% of children with a PDA profile aren't in school or regularly struggle to attend, school and care placements often break down and years of being misunderstood can lead to mental health problems – so it's really important for everyone to have PDA on their radar, as early identification and the right support can make all the difference. There are some case studies and examples of best practice on the PDA Society website.

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As the PDA profile of autism isn't yet well researched and understood, diagnosis can be difficult. We often hear cases of the PDA profile being missed, either because our understanding of how autism presents can still be based on outdated stereotypes, or because demand avoidance isn't recognised.

So the person you're living or working with may have other diagnoses: autism may have been identified, or they may have a diagnosis of ADHD, anxiety, an attachment, personality or conduct disorder, or a range of mental health difficulties ... or a combination of all of those ... or no diagnosis at all.

But what is very likely is that you'll find their presentation perplexing. They may not quite tick all the boxes for any one particular condition, for instance. They may not appear vulnerable – depending on the circumstances they may seem angry or confrontational, or they may mask their difficulties and seem superficially fine but may experience rapid mood changes. It is very likely indeed that they won't respond to conventional interventions or traditional techniques. Indeed, these approaches often hinder rather than help.

Exploring whether a PDA profile of autism could be an underlying factor may hold the answer and signpost a way forward.

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It can be helpful to start by understanding what demand avoidance may look like.

Research from Newcastle University indicates that a hierarchy of avoidance strategies is often seen. These might include ...

- Distraction – “look at that”
- Making excuses – “I can’t do that” or “I don’t know where the saucepan is”
- Physically incapacitating themselves – “my legs don’t work”
- Withdrawing into fantasy – “but I’m a fox and they don’t eat at the table”
- Reducing meaningful conversation – for instance by mimicking the person making the demand or bombarding them with noise ...
- Procrastination – “I’ll do it in a bit ...”
- Sometimes a person may seem completely compliant – maybe role-playing or as a coping mechanism – but this can often be at the expense of emotions later or in a different environment when they feel safe to release the build-up of anxiety
- Or often they will try to be very controlling as a means of coping with anxiety and re-establishing a sense of security. Many children may take on an adult persona using the ‘authority’ that accompanies this to avoid demands (for instance, if they’re the parent or teacher then they’re in charge and can’t be told what to do).

If these avoidance strategies don’t work, or they haven’t been noticed and acted on by those living or working with the individual, there may be a rapid escalation as panic sets in and options run out. This isn’t deliberate choice, it’s a fight, flight or freeze response to anxiety that is a natural instinct we all have. Only at this point, when someone has reached crisis point, might we see them running away, becoming highly agitated, emotional or aggressive, self-harming or shutting down. Meltdowns are best understood as a final uncontrollable panic attack.

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Research is ongoing, but currently PDA is best understood as a profile on the autism spectrum.

Individuals with a PDA profile share similar differences as others on the autism spectrum - social communication and interaction differences, sensory challenges and some restrictive/repetitive behaviours – though sometimes with PDA these traits may present more subtly than might be expected.

The overriding challenge with PDA is extreme anxiety around demands and not feeling in control. So what does that mean in practice? Well, taking each element in turn ...

- Pathological - that means that the avoidance is innate, it’s not a choice or bad behaviour, and it’s extreme enough to be clinically significant
- Demand – demands are ever-present and can take many forms. Significantly, with PDA, it is the everyday demands of life like washing, dressing or eating which provoke anxiety. And not just being asked or told to do something by other people, but also demands we make of ourselves like expectations, thoughts, desires. Or indirect demands such as uncertainty, transitions or praise. And, again significantly, with PDA, the drive to avoid demands isn’t just about things we might not want to do, like homework or housework, but includes things that we do want to do or enjoy.
- Avoidance - with PDA, individuals are driven to avoid these demands to an extreme extent, and demands provoke high anxiety. Autism is dimensional - it impacts different individuals in different ways and can fluctuate in different environments or over time – this applies equally with a PDA profile.

The National Autistic Society describes the distinctive features of a demand avoidant profile as:

- resisting and avoiding the ordinary demands of life
- using social strategies as part of avoidance
- appearing sociable, but maybe lacking understanding
- experiencing excessive mood swings and impulsivity
- appears comfortable in role play and pretence
- displaying obsessive behaviour that is often focused on other people

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So how does it feel to have PDA? Here's what some individuals tell us ...

Jack says *"Although I'm acting angry what I'm feeling is terror, and afterwards I don't remember what I've done."*

Mollie explains *"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."*

For Riko *"PDA is like trying to face your phobias every waking moment!"*

And Isaac, who explains how PDA impacts him in detail on a YouTube video, says *"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 is insisting 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."*

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Now that we understand more about what is underlying pathological demand avoidance in autism, it becomes easier to think about how best to help.

The first and most important point is that conventional approaches - such as praise, boundaries, rewards and consequences - are not only ineffective but actually make things worse.

Whereas negotiation, collaboration, minimal ground rules and careful use of language all help.

We know that with PDA, individuals are highly anxious and unable to tolerate uncertainty, so strategies that keep anxiety to a minimum and provide a sense of control are good starting points.

Always plan ahead, allow plenty of time, pick battles carefully, remain calm and have plan B up your sleeve.

Constant fine-tuning of the balance between the demands being placed on someone and their ability to tolerate demands at any one time is required – there are times when demands need to be minimised and others where they can be increased.

Techniques for making demands feel less direct – including rephrasing requests, providing choices, depersonalising, distracting, using humour and role play – are invaluable.

It's also very important to see the person beyond the condition or behaviours – explore interests and engage positively.

Fairness and trust are central, and if things change be clear and honest about why.

We've produced a simple one-page document called Keys to Care which gives a good overview of these approaches, it can be downloaded from our website.

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To improve outcomes for some of our most vulnerable and misunderstood individuals, the concept of PDA in autism needs to be on everyone's radar.

There is a wealth of information on the PDA Society website (www.pdasociety.org.uk) and on the National Autistic Society website. The transcript from this webinar is also available on the NDTI website.

Thank you for listening. Please don't hesitate to contact us for more information.