

Understanding PDA

Part of the Autism Spectrum



What is PDA?

Research is ongoing – best described as a profile on the autism spectrum

Pathological
Demand
Avoidance

excessive, extreme, can't help it
request to act AND internal 'I ought to'
'giving in' = loss of control = extreme anxiety

aka... Permanent Demand Anxiety

(Margo Duncan)



PDA profile key features

- resists and avoids the ordinary demands of life
- uses social strategies as part of avoidance
- appears sociable but lacks understanding
- experiences excessive mood swings and impulsivity
- appears comfortable in role play and pretence
- displays obsessive behaviour often focused on other people

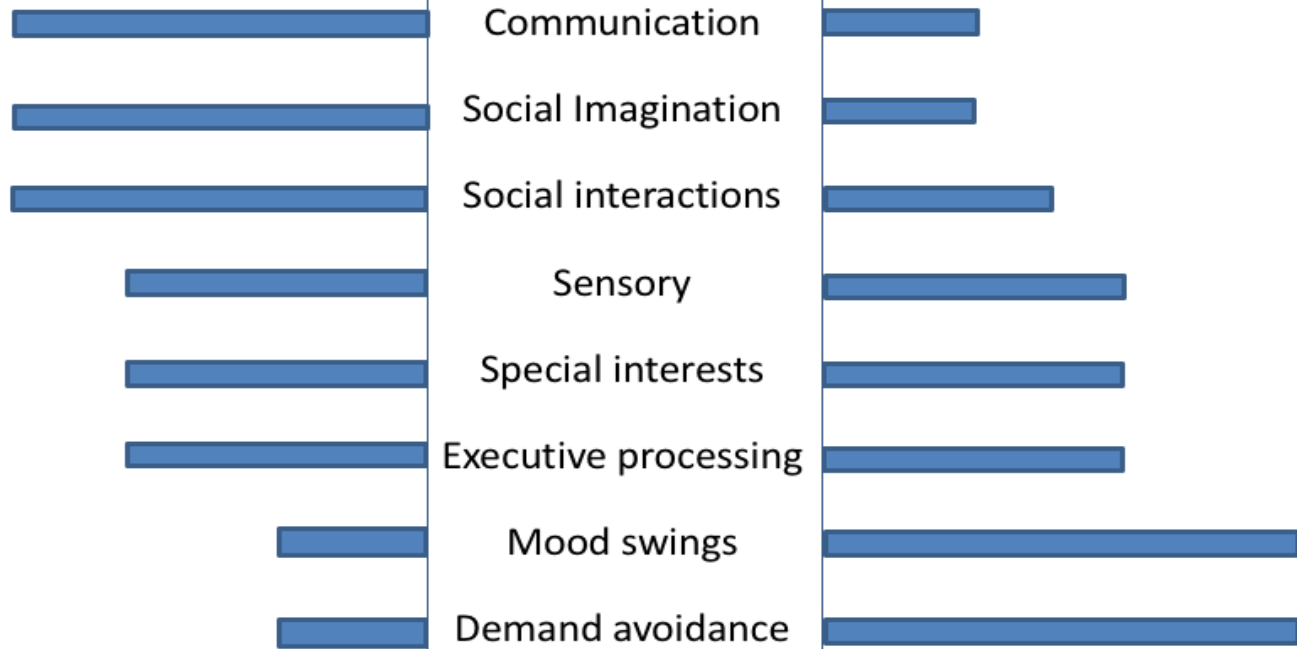


Generalised comparison

Other ASC

Difficulties

PDA



Extreme demand avoidance

Group 1 Non-ASD developmental trauma

- ODD
- Attachment disorder
- Emerging personality disorders

Group 2 ASD with demand avoidance relating to stimuli/environment

Group 3 ASD with a PDA profile

There were clinically identifiable significant differences between these groups, and clear qualitative differences in the nature of the avoidance (which is leading to a new tool)

Eaton (2019)



Why distinguish?

The underlying causes of the behaviour are somewhat different and require **different strategies** when providing support.

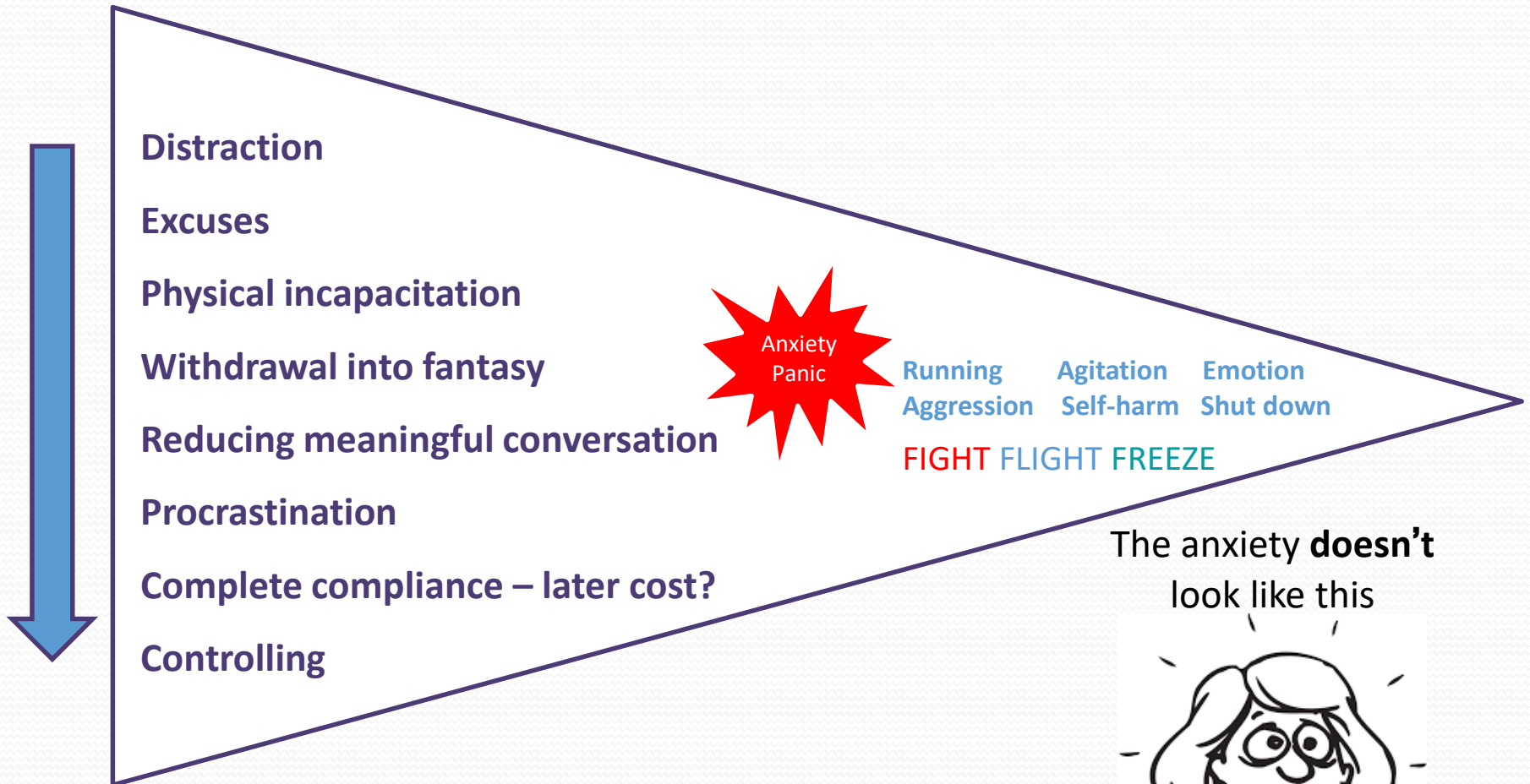


What is being avoided?

- Individuals may struggle with simple activities: eating, drinking, washing, dressing, going out, doing work
- The demand avoidance also combines with other autistic traits affecting socialising and surviving in a stressful environment
- Demand avoidance also applies to things people WANT to do e.g. trips out, seeing friends
- Adults and children face exactly the same difficulties



What demand avoidance may look like



The anxiety **doesn't**
look like this



Mental Health

Mood swings

Jeckyll and Hyde persona

'one thing that's predictable is the unpredictability'

Poor sense of identity

Driven by a lack of identity and sense of self

"If I let others dictate, that negates my sense of self"

Anxiety

Usual therapies are ineffective

Depression

'No way out' is demoralising



Physical health

Sensory difficulties

clothes, creams and soaps, flavours

Interoception difficulties – internal senses

hunger, thirst, temperature, identity

Exhaustion from mental / physical activity



What helps?

1. Reduce demands (including expectations)
2. Change the *experience* of demands
3. Increase tolerance to demands when possible

This means helping someone to do what they can, doing some stuff for them and accepting that some things can't be done.



Unusual Support Style

‘Good parenting’ is ineffective

- ✗ Clarity
- ✗ Firm boundaries
- ✗ Rewards & consequences
- ✗ Praise (positive reinforcement)

What works can look like ‘bad parenting’

- ✓ Flexibility
- ✓ Few boundaries
- ✓ Negotiation
- ✓ Indirect affirmation

In summary...relationships

- It is essential to adapt responses to reduce tensions
 - Be aware that onlookers confuse cause and effect
 - It isn't the same as doing everything for a PDA individual – it's about also making it possible to do more.
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- A positive relationship is very helpful for good outcomes
 - Needs to be built on shared interests, fairness and trust
 - Carers need support and protection from burnout



In summary... Communication

A change in mindset means the way you communicate becomes very different.

- Most institutions and professional interactions are naturally aversive with procedures and need for compliance with expected norms
- A person-centred approach works best, supporting individuals as equals



Helpful approaches

- Understand the source of behaviour
- Few rules, but predictability from others
- Take time and plan ahead (have Plan b & c)
- Indirect communication & non-directive language
- Novelty and variety / use of humour
- Gentle affirming with less direct praise
(‘it’s looking tidier in here’ rather than ‘well done for tidying up’)
- ‘Plant seeds’



Self help - Tricking the mind

- Doing the opposite
- Avoidance eg making a list
- 'You don't have to' / Deciding not to
- My choice / having some control
- Role play – pretend you are being filmed
- Not thinking
- Mixing it up - doing things differently

DragonRiko



In summary : Good support

- Working in partnership – enabling and collaborating, being creative and using interests where possible
- Being ‘in-tune’ with anxiety levels
- Development of anxiety self-management
- Develop new supportive relationships and positive activities





- **Further info** at www.pdasociety.org.uk
- PDA Society **enquiry line** info@pdasociety.org.uk
- **Facebook:** [thepdasociety](https://www.facebook.com/thepdasociety)
- **Twitter:** [@PDASociety](https://twitter.com/PDASociety)
- Remember the panda 😊
- Any other questions?

