

Keys to care

Supporting people with a PDA profile

The term PDA stands for **Pathological Demand Avoidance**. This is widely understood to be a profile found within some autistic people. The most obvious characteristic of PDA is a determined avoidance of so-called 'common' demands of life, including expectations and things the person enjoys doing.

This avoidance is often driven by **anxiety** or a **stress** response to demands, rather than choice. PDAers may describe it as a tug of war between **brain**, **heart** and **body**.

Key points:

- traditional support approaches can often cause more harm than good
- processing may take longer so patience is important
- trust, consistency, warmth and honesty are key
- equitable relationships grounded in shared power help reduce anxiety
- distressed behaviour is an anxiety response and a means of communicating
- collaboration, flexibility, variety and humour can often work well

Avoidance:

- avoidance isn't a choice
- everyday tasks can be a real struggle
- feeling out of control can create extreme anxiety which can present in different ways

What helps?

- indirect requests and communication
- support to initiate and carry out tasks, particularly those which are essential for health/wellbeing
- approaches which are collaborative, flexible and variable
- respecting a 'no' - when a person can't, they can't

Sensory processing:

- hyper-sensitivity to things such as light, noises, smells, touch, foods leading to sensory overload
- hypo-sensitivity meaning that more sensory input is required and leading to sensory seeking
- challenges when interpreting what the body is signalling such as hunger, thirst or pain

What helps?

- assessing sensory needs
- implementing sensory adjustments to meet need
- awareness and understanding of how sensory challenges can impact behaviour

Mood and behaviour

- changes in mood can sometimes happen quickly for PDAers
- distressed behaviours can occur when an individual has run out of capacity and is overwhelmed
- behaviours may include meltdowns, shutdowns, aggression, self-injury or flight type responses
- in crisis communication and reasoning may not be possible

What helps?

- framing distressed behaviours as a panic attack
- responding calmly
- understanding what helps and offering appropriate support
- monitoring capacity levels and proactively helping to lower demands
- allowing time to recover and rest afterwards

Routine and transition

- some degree of routine can be useful provided there is flexibility
- unexpected changes around plans, people or environments can be triggering
- moving from one activity or environment to another may cause dysregulation

What helps?

- including the individual in the process of creating their own routine or plan
- being patient and allowing time for transitions from one place or activity to another
- giving plenty of notice when things are coming to an end, or if there are going to be changes to a plan
- taking time to ask and understand what helps

Activities and interests:

- trust and connection can be built through sharing special interests
- taking time to ask and genuinely engage with areas of interest
- suggesting ideas and/or activities related to special interests
- understanding that even activities that a PDAer really wants to do are still a demand and can be challenging
- being flexible and gently encouraging to support the individual with being able to access the activity

Find out more:

We have further practical information to help you support PDAers on our website:

<https://www.pdasociety.org.uk/research-professional-practice/>

