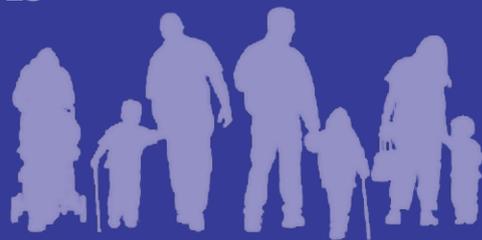


# PATHOLOGICAL DEMAND AVOIDANCE (PDA)

This fact sheet has been written by parent carers for parent carers.  
Clinical information has been approved by West Sussex practitioners.



## What is Pathological Demand Avoidance (PDA)?

Pathological Demand Avoidance (PDA) is understood to be a profile on the Autism spectrum involving the extreme avoidance of everyday demands, often using social tools and strategies to do so. Autism is a lifelong developmental condition which affects social interaction and social communication. Other characteristics can include social anxiety, repetitive or obsessive behaviour and interests, and sensory processing differences.

Research on PDA is still in its infancy and without an agreed definition it is not currently recognised as a separate diagnosis from Autism. Identification of a PDA profile on the Autism spectrum, however, can help to pinpoint a child's specific support needs. Understanding how avoidant behaviours with PDA are often related to 'demand anxiety', can be particularly useful in finding the right strategies to help them.

## Characteristics of PDA

People with a PDA profile will present with Autistic characteristics but will also display many of the following features:

- A need to control, always anxiety-related
- Resisting and avoiding everyday demands including things they enjoy or want to do
- A tendency to use social approaches, for example, using distractions or giving excuses to avoid demands
- Appearing sociable but having underlying difficulties in social communication and interaction
- Experiencing excessive mood swings and impulsivity
- Appearing comfortable with role play, pretence and fantasy
- Displaying obsessive behaviour that focuses on other people
- A tendency not to respond to conventional approaches to parenting, teaching and other support.
- Meltdowns, which can be interpreted as a form of panic attack due to the high levels of anxiety causing the meltdown

## Support strategies for PDA

Conventional strategies to support Autism (e.g., rewards, structure & routine) are often ineffective with a PDA profile because they can place implicit demands or expectations on a child. The PDA Society (listed under further reading below) therefore recommends a 'person-centred approach, based on negotiation, collaboration & flexibility'. Careful use of language, offering a sense of control and keeping anxiety to a minimum is also encouraged. They use the word 'P.A.N.D.A.' to help remember key approaches for supporting children with PDA:

- PICK BATTLES – minimise rules, enable some choice and control, explain reasons, accept that some things can't be done.
- ANXIETY MANAGEMENT – use a 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 – keep calm, proactively collaborate and negotiate to solve challenges; fairness and trust are central.
- DISGUISE & MANAGE DEMANDS – phrase requests indirectly, monitor tolerance for demands and adapt accordingly; doing things together helps.
- ADAPTATION – 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.





## PATHOLOGICAL DEMAND AVOIDANCE (PDA)

### Assessment of PDA

A PDA profile is usually identified during an assessment for Autism but owing to a lack of consensus on the definition of PDA, the term itself may not necessarily be employed by clinicians. However, through a detailed assessment for Autism it should be possible to identify your child's strengths and challenges and the support they need regardless of what terminology is used.

### Ask About

- **Aspens** – Autism charity in West Sussex offering behavioural advice services, parent workshops, children's groups and sibling support. Visit [www.aspens.org.uk](http://www.aspens.org.uk), or call: **01892 822 168**.
- **Autism and Social Communication Team (ASCT)** – Specialist teachers that schools can refer to for expert advice about the educational, social and emotional development of pupils with ASC. See: <https://westsussex.local-offer.org/services/114-autism-and-social-team-inclusion>.
- **Brighton and Hove PDA Forum** – a forum covering the Sussex NHS area for parents of those with PDA. Go to: <https://pdahelp.wixsite.com/brightonhovepdaforum/forum-1>.
- **Learning and Behaviour Advisory Team (LBAT)** – Offers consultation & training to schools around learning and behaviour when a pupil's progress is being affected by these issues. Ask your child's school for details & visit: <https://westsussex.local-offer.org/services/229>.
- **PDA Support Sussex (East & West)** – Facebook group offering support to parents and carers: [www.facebook.com/groups/pda.support.sussex](http://www.facebook.com/groups/pda.support.sussex).
- **Reaching Families** – provides training, information & other fact sheets related to this topic. See especially our training on *Understanding Demand Avoidance* and *Understanding Autism*. We also offer benefits advice, peer support, a Facebook group & handbook (see below) for parent carers of children & young people with SEND in West Sussex. See: [www.reachingfamilies.org.uk](http://www.reachingfamilies.org.uk).
- **Single Point of Access (SPoA) West Sussex** - a dedicated route to access specialist emotional wellbeing and mental health support for those aged 4-17. Anyone can refer to SPoA including children & parent carers. Referrals will be directed to the most appropriate help from Youth Emotional Support, YMCA Dialogue or Sussex Child and Adolescent Mental Health Services (CAMHS). Alternatively, signposting to other sources of support may be given. To make a referral, use the online form at: <https://e-wellbeing.co.uk/support> or Tel: **0300 304 0462**.
- **West Sussex Children's Services** – support from health and social care. If your child is under 18, contact the Integrated Front Door (IFD) for West Sussex Children's Services. Tel: **01403 229900** or email: [WSChildrenservices@westsussex.gov.uk](mailto:WSChildrenservices@westsussex.gov.uk). The IFD is also an entry point for the Children with Disabilities (social care) service for children & young people with severe and/or complex disabilities. Eligibility criteria apply – See: <https://westsussex.local-offer.org/services/265>. For over 18s call the Adults' CarePoint: **01243 642121**, or email: [socialcare@westsussex.gov.uk](mailto:socialcare@westsussex.gov.uk).

### Further reading and useful links

- ***Making Sense of it All: From Birth to Adulthood*** – Reaching Families' handbook for parent carers of children and young people with SEND in West Sussex. This provides essential information on money matters, including claiming DLA and PIP, as well as social care, health, leisure, travel, education and employment. Go to: [www.reachingfamilies.org.uk/guides.html](http://www.reachingfamilies.org.uk/guides.html).
- **National Autistic Society** – for information and resources go to: [www.autism.org.uk](http://www.autism.org.uk).
- **The PDA Society** – for information and resources go to: [www.pdasociety.org.uk](http://www.pdasociety.org.uk).
- **West Sussex Libraries** – For a list of books on this topic available to borrow for free with a West Sussex library card go to: <https://arena.westsussex.gov.uk/welcome> and search the library catalogue for 'pathological demand avoidance'. See especially 'Understanding Pathological Demand Avoidance', published by Jessica Kingsley (also available at <https://uk.jkp.com>).
- **West Sussex Local Offer** – go to <https://westsussex.local-offer.org> for local services, support and details of *Short Breaks* providers for children & young people aged 0 - 25 years with SEND.

