

PDA PARENTING

Documents to support PDA families

TOP TIPS: PATHWAYS TO A PDA DIAGNOSIS

Pathological Demand Avoidance (PDA)

Pathological Demand Avoidance is a profile that fits into the autism spectrum, otherwise referred to as an Autism Spectrum Disorder (ASD) and is thought to be rooted in an ***anxiety-based need to be in control***. It has a distinct set of features that may not always be commonly associated with autism.

According to the **National Autistic Society**, a person with a demand- avoidant profile may require a great deal of support and understanding. The sooner the profile is recognised the more chances the appropriate support can be put into place so that the outcomes are more positive.

Controversy around a PDA diagnosis

PDA is a relatively recent profile and there is still a degree of contention amongst professionals on it's current status; ongoing research should help shape a future consensus.

However, it is still specified in the NICE guidelines that as part of every autism diagnostic assessment a profile of strengths, skills, impairments and needs are specified; demand avoidant behaviour being part of them. Autism should not be ruled out, for example, if there is good eye contact, smiling, pretend play or normal language milestones (NICE Pathways 2017).

1

RESEARCH

Prepare yourself by reading, attending workshops, courses or conferences on PDA. Any research you can do to better equip your knowledge will help.

2

PRACTICE

Alter your parenting approach to PDA strategies - this is important to record if they are successful: www.pdasociety.org.uk/families/strategies

3

EVIDENCE

Document everything; keep a diary, any triggers, unusual behaviours or lability of mood swings. The EDA-Q may show a demand avoidant profile.



NHS Local Pathway

A referral can be made from your GP to your local NHS diagnostic team.



NHS Specialist Referral

You can request an onward referral to an NHS specialist within this field, with knowledge of PDA.



Private Route

The PDA Society has a list of independent autism diagnostic centres who diagnose PDA in accordance with NICE pathways.

POSITION STATEMENT ON PATHOLOGICAL DEMAND AVOIDANCE

The autism strategy, **Think Autism**, was published in 2014 and recommends that every clinical commissioning group go forward to commission a diagnostic care pathway for autism in its area, and that; *“people considered to have a PDA profile should also be able to get support from their GP and a referral for a diagnosis if appropriate.”* This is useful to quote when seeking a referral and if told that your area will not recognise PDA. The recent position statement, released from the **Department of Health and Social Care**, states *“the lack of consensus on the status of PDA profile should not be a reason to fail to identify and consider how best to meet the support needs of an individual.”*

Difficulties with an incorrect diagnosis

PDA is often misdiagnosed with a range of diagnoses such as Oppositional Defiant Disorder (ODD), pervasive developmental disorder not otherwise specified (PDD-NOS), Reactive Attachment Disorder (RAD) and sometimes parents can even be accused of fabricated or induced illness (FII).

What is important, however, is that the framework of strategies differ for an individual with PDA. Support for ODD, for example, will follow a positive behaviour management plan and these are proven to be counter-productive to an individual with PDA; understanding that the individual can't help that they won't is key. Using a scheme of rewards and punishments will only increase the anxieties of the individual and lead to poor outcomes. A diagnosis is only useful if it signposts the correct support.



Know your rights!

Seeking a correct diagnosis can often enable an individual to access services, support or bespoke strategies that are essential to their wellbeing. It is imperative that the individual is adequately supported in order to thrive.

It is worth thinking you have the right to raise any concerns about the care or assessments so far, whether to your local

Clinical Commissioning Group (CCG) or via the Patient Advice and Liaison Service (PALS), in order to request a more befitting diagnostic pathway. One may argue that it is disability discrimination if you are being prevented an appropriate assessment, or if it is inadequate, simply by the area that you live in. It will require knowledge, evidence and perseverance but knowing your rights is important.

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