

# A few golden rules: strategies that may help at home

## **Choose your battles carefully**

Focus on a few important boundaries like safety issues. Learn to 'let go' of things that are not important. Consider: is it worth a meltdown?

## **Balance tolerance and demands**

Every day is different for children with PDA. When anxiety is high, demands should be few. When your child is more relaxed, demands can be increased.

## **Don't take it personally**

Children with PDA are driven by anxiety. They can say and do things that are hurtful. Understand that the 'root cause' of this behaviour is their high anxiety.

## **Use indirect demands or requests**

Challenges are great for getting things done. For example, "Race you to the bathroom – bet I can wash my face before you!"

## **Offer limited choices to give the child a sense of control & autonomy**

Saying "do you want to have a bath or a shower?" communicates the need to wash but offers a choice, which helps to reduce anxiety.

**Individuals with PDA also have many strengths and qualities, such as being creative, affectionate and focused on things that interest them. These can often be used to capture their interest, disguise demands and lower anxiety levels.**

# Do you suspect your child has PDA or has your child recently been diagnosed with this condition?



The **National Autistic Society** (NAS) website has a useful guide to the PDA profile, which can be given to family members, teachers and other professionals who may be involved in supporting your child. Search for 'PDA' on the NAS website [www.autism.org.uk](http://www.autism.org.uk)

You can find more **advice and support** via the PDA Society website [www.pdasociety.org.uk](http://www.pdasociety.org.uk)

- Case studies, books and other resources
- Links to external websites, Facebook groups and blogs
- A discussion forum and a parent enquiry line
- Useful strategies and dealing with meltdowns
- Information about diagnosis

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# A Parent's Guide to Understanding Pathological Demand Avoidance (PDA) - Part of the Autism Spectrum



# What is Pathological Demand Avoidance?

**PDA is a diagnostic profile** that is seen in some children on the autism spectrum. Children with a PDA Profile will share difficulties with others on the autism spectrum in the following areas:

- a. Social Communication Difficulties
- b. Social Interaction Difficulties
- c. Restrictive and Repetitive patterns of behaviour, activities and interests

Children may also have other conditions alongside their PDA, for example Sensory Issues, Dyslexia, Dyspraxia, Attention Deficit Hyperactivity Disorder (ADHD) and Mental Health issues.

Children who present with the PDA profile are driven to avoid everyday demands and expectations to an extreme extent. **“PDA is best understood as an anxiety driven need to be in control and avoid other people’s demands and expectations.”** *Understanding Pathological Demand Avoidance in Children. Christie, Duncan, Fidler & Healy (2011).*

**Even ordinary daily tasks** such as getting dressed, eating a meal and going out (even to an enjoyable place) **can be very challenging** for a child with PDA. They will often go to extreme lengths to avoid demands – this is what is meant by the term ‘pathological’.

A child with PDA might **avoid demands in lots of different ways** from simply refusing, making an excuse, distracting, negotiating or doing / saying something shocking. If these avoidance strategies fail, the child may have a **meltdown**, which is best viewed as a panic attack. This may take the form of challenging behaviour, withdrawal or some children may run away.

# Characteristics of the PDA profile

Children with PDA can appear to have **better social understanding and communication skills** than others on the autism spectrum. This means that some of their difficulties may be less obvious at first.

Also, some children may **‘mask’** their true difficulties in this area and it’s usually the **surface sociability and often vivid imagination** of children with the PDA profile which confuse professionals regarding a diagnosis of an autism spectrum disorder.

## The key features of a PDA profile are:

- Resisting and avoiding ordinary demands
- Appearing sociable but lacking depth in understanding
- Excessive mood swings and impulsivity
- Comfortable in role play and pretend, sometimes to an extreme extent
- Obsessive behaviour, often focused on real or imagined people.

The behaviour of children with a PDA profile can vary between settings or at different times e.g. **a child can be anxious at home, but appear calm at school.** This may be a coping strategy for the child. In other children, the **demands at school can lead to severe ‘meltdowns’** within the school environment and/or school refusal. This can be difficult for both teachers and parents alike.

A lack of understanding about the reasons for these difficulties can make **parents feel isolated & inadequate.** Many parents may feel that they have been wrongly accused of poor parenting.

Rather, it is about a child with a **‘hidden disability’** trying hard to fit into a world they find confusing but long to be a part of.

# How do I tell if my child has PDA?

**Autism is dimensional and the different profiles, including PDA, affect people in varying ways and to different degrees.** It is when many of the key features of the PDA profile appear together, in conjunction with the common difficulties shared with others on the autism spectrum, that it is helpful to have a diagnosis of the PDA profile because this has **implications for successful intervention and management.**

The Extreme Demand Avoidance Questionnaire (EDA-Q) can help to identify individuals with an elevated risk of having a profile consistent with PDA and is available on our website at [www.pdasociety.org.uk/resources/extreme-demand-avoidance-questionnaire](http://www.pdasociety.org.uk/resources/extreme-demand-avoidance-questionnaire)

**Please note**, the EDA-Q should not be considered a diagnostic test. For diagnosis, a thorough assessment by an experienced professional is required.

## Assessment and Diagnosis

The earlier the recognition of the PDA profile, the sooner **appropriate support** can be put into place.

If you feel that your child may have an ASD with a PDA profile, make an appointment to see your GP and provide **plenty of supporting evidence.** Request that your child is referred to an appropriate service that can assess for an **autism spectrum disorder.** Not all clinics will be familiar with the PDA profile and so onward referral may be required. You can find more information about the diagnostic process on our website.