

## **Advocating for Your PDA Child, Teen, or Loved One**

Empowerment, Education, and Understanding -Neurodiverse Adventures-

### **What is Pathological Demand Avoidance (PDA)?**

PDA is a profile on the autism spectrum characterised by an extreme avoidance of everyday demands and a need for control. This often stems from high anxiety and can present as strong resistance, social strategies to avoid demands, and difficulties with traditional support approaches.

Understanding PDA is the first step towards effective advocacy.

### **Step 1: Understanding & Acceptance**

- PDA is a Hidden Disability: Many children and teens with PDA appear outwardly “fine” but are experiencing intense internal anxiety. Their behaviours are often misunderstood because their disability is invisible.
- It's Not “Won’t”—It’s “Can’t”: What looks like refusal is often a neurological inability, not a choice. Demands can trigger panic responses or overwhelm, making agreement impossible in the moment.
- Reframe Parenting and Belief Systems: Standard parenting techniques—like reward charts or consequences—often backfire. Supporting a PDA child means letting go of control and using relationship-based, curiosity-driven approaches.
- Change Your Language, Change the Outcome: Using indirect, non-demanding language and offering choices helps reduce anxiety and avoids triggering avoidance or meltdowns.
- Validate Their Experience: Recognise that avoidance behaviours are not defiance—they’re anxiety-driven responses to perceived loss of autonomy.

### **Step 2: Advocating for Assessments**

#### **Carer’s Assessment**

- Purpose: To evaluate your needs as a carer and ensure you receive support.
- Where to Apply: Contact your local authority’s adult social care team.
- Tips:
  - Emphasise the emotional and physical toll.
  - Keep a diary/log of daily challenges and support needs.
  - Use the language of “need”, “impact”, and “risk”.

### Needs Assessment for Your Child/Teen

- Purpose: To determine what social, medical, or educational support they require.
- Steps:
  - Request an assessment under the Children and Families Act 2014.
  - Gather reports from educational psychologists, speech and language therapists, and occupational therapists.
  - Highlight PDA-specific traits and how they affect daily functioning.

Educate yourself about the legal duties your local authority is required to fulfil and be prepared for being fobbed off.

### **Step 3: Navigating Education**

- Request an EHCP (Education, Health and Care Plan):
  - Submit a formal request to your local authority.
  - Detail how your child's PDA affects their access to education.
  - Advocate for individualised, flexible accommodations.
- Support Tips for Schools:
  - Reduce demands, offer choices, and use indirect language.
  - Avoid traditional behavioural strategies like sticker charts or sanctions.
  - Educate staff about PDA and anxiety-informed practice.
- If School Isn't Working:
  - Consider alternatives: EOTAS (Education Other Than At School), flexi-schooling, or specialist provision.
  - Seek legal advice if necessary.

### **Step 4: Educating and Involving the Family**

- Open Conversations:
  - Share books, articles, or videos that explain PDA in accessible language.
  - Use metaphors: "Imagine every demand feels like walking into a fire."
- Model Empathy:
  - Show how shifting perspective helps.
  - Help family members adjust expectations and avoid power struggles.
- Set Boundaries:
  - Protect your child from judgment or invalidation.
  - It's okay to limit contact with people who refuse to understand.

### **Step 5: Look After Your Own Wellbeing**

- Advocacy Requires Energy: Supporting a child with PDA can be mentally and emotionally exhausting. Your ability to advocate effectively is tied to your own well-being.
- Prioritise Self-Care: You cannot pour from an empty cup. Find time for rest, hobbies, support networks, or professional help if needed.
- Seek Connection: Surround yourself with people who understand and support your journey. You deserve validation too.
- Be Kind to Yourself: There's no such thing as a perfect parent or carer. Your persistence, love, and commitment make all the difference.

### **Need Guidance Through Coaching?**

Contact Amanda at Neurodiverse Adventures

 [amanda@neurodiverseadventures.com](mailto:amanda@neurodiverseadventures.com)

For 1:1 guidance, coaching, and advocacy support tailored to your journey.

\*You are not alone. Advocating for someone with PDA is a journey of deep understanding, creative thinking, and unshakable love. Your voice matters—keep speaking up.\*