



Defining & Supporting PDA, Pathological Demand Avoidance

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Currently PDA is understood as an autistic profile that is gaining recognition in the United States. PDA children and adults avoid everyday demands using ‘social strategies’ as part of the avoidance, have a strong need for autonomy and control, require unique supports and are socially oriented. These highly stress-prone individuals are often not recognized as autistic, are deeply misunderstood and in need of support.

PDA is an acronym that stands for Pathological Demand Avoidance or Pervasive Drive for Autonomy. The first being the original and prominent name where the latter is newer and preferred by many individuals. PDA was identified in the UK in the 1980s. It has recently gotten more attention in the US and Canada since PDA North America was established in March 2020. Many families, educators and therapists have not heard of PDA. Since it is not in the DSM as a stand alone diagnosis, many professionals do not accept it as a diagnosis. But things are changing and many psychologists will now include PDA as a “profile” of autism in an assessment.

A PDA profile shares common autistic traits. These common traits include:

- Sensory differences
- Lack of Interoceptive awareness
- Difficulties with social understanding
- Obsessive traits (PDAers obsessions are often on people vs. things) and can have strong interests
- May focus on details instead of the big picture, including less important details
- Struggles with emotional regulation
- Anxiety

Traits not shared with non-PDA autism:

- More frequent eye contact
- Many have adaptive social skills with blind spots
- Like spontaneity
- Dislike most routine
- Rewards, including praise, can be triggering
- Are unorthodox and imaginative
- More expressive empathy
- 50% male / female
- Triggers are both predictable and unpredictable
- Some instinctively mask or camouflage distress



Key features to a PDA Profile can include:

- A fundamental need for control
- Resisting and avoiding the everyday demands of life like eating, drinking, sleeping, toileting
- Using social strategies as part of everyday avoidance (“My legs don’t work!”)
- Avoidance even of things they like and want to do
- Experiencing changes in mood and impulsivity due to hyper-vigilance, sensitivity, and intensity of emotions
- Appearing sociable but lacking some understanding or skills in navigating situations or relationships
- Rewards and consequences feeling like pressure
- Difficulty complying with requests of others
- Enjoying pretending and role play
- Not appreciating hierarchy or age differences
- Seeming very interested in social interactions
- Sometimes acting very differently in different environments
- Appearing dominating and controlling, especially when feeling anxious
- Feeling confident and engaging when they feel secure and in control
- Seeming callous, but feel deeply or may be oblivious of their impact on others

Key factors to understand with PDA:

- PDA is not ODD and is often misdiagnosed
- PDA is not a stand-alone diagnosis, nor is it a side effect of executive dysfunction or broader unsupported autistic needs
- People who fit this profile share similar characteristics but each person is an individual and it’s not a one-size-fits-all approach
- Traditional supports and interventions for autistic individuals do not work and can make things worse for a PDA person
- PDA people’s sensitive nervous systems and can easily go into fight, flight, fawn or freeze states
- PDA individuals frequently ‘mask’ to fit in, therefore teachers and professionals can easily miss that they need support, especially in educational or diagnostic settings
- Avoiding demands is not a choice for individuals on the profile. It is a matter of “can’t” not “won’t”



What is considered a 'demand' for PDA?

Demands in PDA are everywhere and cumulative. Because of this, PDA people have fluctuating capacity depending on the demands placed on them in any given day. To better understand this, it can be helpful to think about some of the different 'types' of demands.

Direct Demands from people can include:

- "Wash your hands"
- "Put away your laundry"
- "Stand up"
- "Start your homework"

Casual Demands:

- "Let's watch a movie"
- "We need to stop and pick something up for dinner"
- "Let's go get ice cream now"
- "We need to hurry and leave for the airport"

Demands based on expectation:

- Going on a family outing
- Following the rules of games, sports etc.
- Leaving the house for an appointment, school, etc.
- Homework for school
- Praise - "Great job! You did awesome!" - this can feel like a demand to do just as good the next time and be crippling

Self-imposed demands:

Wanting to do a task or activity but not being able to start or complete it due to excitement or personal expectations. This can be from taking a shower, eating a meal, brushing teeth, reading a book, hobbies, answering a text or talking.



How are demands avoided in PDA?

Pathological demand avoidance is all-encompassing and has some unique aspects.

Individuals with PDA will use a wide range of avoidance strategies:

- Manipulating social situations to remain in control.
- Refusal: “I can’t do it”, “You can’t make me”
- Making excuses: “My arms aren’t strong enough!”
- Distraction: “I heard a funny joke today!”
- Arguing
- Negotiating
- Delaying: “I’ll do it later or tomorrow”
- Proposing other options
- Using make believe

How are demands avoided?

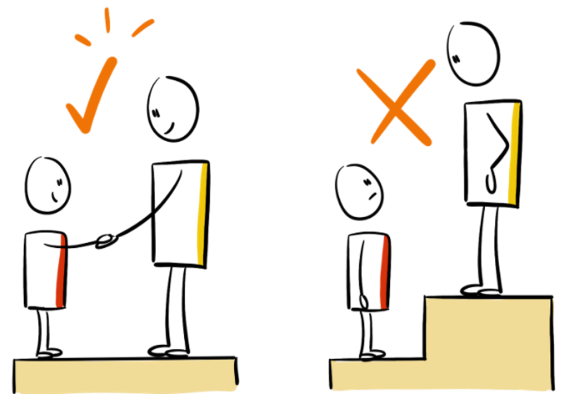
- Fight: Defensive verbally or physically
- Flight: Remove themselves from the situation, may elope
- Freeze: Shutdown - inability to fight, flight or fawn
- Fawning: Compulsive dominating or submitting (or alternating depending on setting!)
- Fibbing: Compulsive lying, confabulation
- Funster: Compulsive, sometimes inappropriate joking
- Forgetting: Blanking out, disassociating
- Flopping: Fainting, sleeping, “legs don’t work”
- Fantasy: Escapism, maladaptive daydreaming



Key Supports for PDA

Respect & connection are everything!

- It is a mindset not a strategy
- Choose priorities
- Use indirect language including thinking aloud
- Have PDAers plan their own schedule and routines
- Be spontaneous
- Use humor
- Listen to understand
- Focus on a genuine relationship
- Collaborate - utilize partnerships
- Share tasks
- Show them you're equals, not above them
- Realize that stress is cumulative
- Understand that emotions are contagious!
- Empathy but be careful
- Realize you must EARN their trust
- Allow them to behave in ways they feel most comfortable (don't push to mask or unmask)
- Help things make sense - they may not be able to act unless it makes sense, they need to know the deep why behind most things
- Whatever the ask, it has to be worth the energy and stress
- Model how to understand ourselves, especially how their bodies respond, processing feelings and thoughts
- Teach them how to communicate about themselves and their needs to others
- Don't pressure
- Don't push
- Don't ignore





Key Supports for PDA, cont.

- Challenging behavior is only a sign or signal that there is a problem. It is not the problem (*Ross Greene*)
- Behavioral approaches (*including looking for antecedents*) don't work
- **PDA individuals go from 0 to 60 in a minute because their baseline is 50**
- So many times, concerning behavior is caused by their trying to meet our needs and comply such as negotiating
- Every task has to be worth the stress and energy-individuals need to calculate this-it has a cost. *Is the juice worth the squeeze?!*
- We can't always make things better, but we can avoid making things worse

What NOT to do...

- Resist the urge to give consequences or threaten them
- Don't worry about holding them accountable
- Don't lecture or talk too much - less is more
- Don't dismiss their reality
- Try not to convince them otherwise
- Don't remind them of rules and expectations
- Don't express disappointment or shame
- Don't get stuck on that you are letting them "get away with it"

Use Declarative Language

- Adult is commenting aloud while doing things - not giving direct orders
- Adult can share observations they notice - "that snow looks cold"
- For when there is no specific need and assumes there is no correct or incorrect response
- Can be direct (proposing detailed possible options) or indirect (no suggested courses of action)



Key Supports for PDA, cont.

Easy ways to use declarative language start with...

- I wonder...
- I noticed...
- I imagine...
- I'm thinking...
- I am worried that...
- I remember...

Tolerance VS Demand - looking under the iceberg:

Behavioral challenges are the “tip” of the iceberg, and the answers to helping children are often found below the surface of behaviors. The tip of the iceberg will tell us “what” is happening, but not the “why”.

What you can see...

Behavioral challenges

Why it's happening...

Demand anxiety

Medication Side Effects

Social Differences

School history of punitive disciplinary measures

Auditory processing delays

Sensory Processing Differences

Sleep Disruptions



PDA Burnout

Many people come to learn about PDA through burnout which can be defined as a marked decline in coping mechanisms due to accumulated stress from navigating daily demands.

Recognizing PDA Burnout:

- Observing significant increases in avoidance behaviors
- Extreme mood swings
- Experiencing previously enjoyed or tolerated activities as demands
- Heightened anxiety
- Social withdrawal
- General sense of overwhelm, often triggered by perceived demands or expectations, even if seemingly minor, which can manifest as meltdowns, shutdowns, or "taking flight" behaviors essentially

Burnout Impacts:

- Capacity
- Personality
- Intensity of mood swings

Supporting Burnout Requires:


- Lowest demands possible
- Long recovery time (months to years)
- Low-pressure re-introduction to life
- Educating others in their life about burnout and how to support it


Keeping Cool is KEY!

- The hardest part of all of this but necessary!
- PDA people can't regulate their emotions if they are not emotionally regulated
- Fight the punitive part of yourself
- Be honest about your own struggles along the way; you can't be perfect but you can grow alongside your child



PDA North America is a 501(c)(3) non-profit organization that has supports and resources for Pathological Demand Avoidance/ Pervasive Drive for Autonomy. We provide resources for families, professionals and PDA individuals.

 www.pdanorthamerica.org

 learn.pdanorthamerica.org

PDA North America Resources:

- **PDA Learning Lab** - self-paced pre-recorded webinars & trainings - <https://learn.pdanorthamerica.org/>
- **Annual Conference** - March 5-7th Virtual & In-Person outside Chicago
- **PDA Insights Articles** - Articles posted regularly on various PDA topics - <https://pdanorthamerica.com/insights>
- **PDA-Affirming Provider List** - over 500+ providers that consider themselves PDA-affirming, sorted by state/province - <https://pdanorthamerica.org/pda-affirming-providers/>
- **Upcoming Webinars & Events** - details and registration for all upcoming announced offerings - <https://pdanorthamerica.org/events/>
- **Parent Provided Educators List** (if you have a PDA child that goes to an educator that is PDA affirming, we'd love for you to submit them to be listed!) <https://pdanorthamerica.org/pda-affirming-providers/>
- **Free Peer Support Groups** - support groups that meet regularly - <https://pdanorthamerica.org/support-groups/>
- **YouTube Channel** - <https://www.youtube.com/@PDANorthAmerica>
- **Free Downloadable PDF Resources** - free downloadables - <https://pdanorthamerica.org/free-pdfs/>
- **PDA Community Contact List** - parents and PDAers seeking a local community of people that understand and value their experience - <https://pdanorthamerica.org/community-list/>
- **Support Shop** - PDA Swag shop - <https://pdanorthamerica.org/support-shop/#products>



Connect with PDA North America:

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PDA North America Mission:

Our mission is bold. We want to spread awareness of PDA (Pathological Demand Avoidance/Pervasive Drive for Autonomy) to parents, individuals, educators and therapists throughout the US and Canada. We want to create resources for families to have a place to turn for support and guidance. We want professionals to be able to receive training, consultation and information in order to effectively teach or treat PDAers. And we want PDAers to know that they are understood and supported. In short, to build a strong and vibrant community for this underserved population.

With your support and donations, we will continue to grow and offer more support services and programming for the PDA community. The sky is the limit.

PDA North America is a non-profit organization with 501(c)(3) status. All donations are tax-deductible.