



Understanding & Supporting PDA, Pathological Demand Avoidance

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PDA is an acronym that stands for Pathological Demand Avoidance, or as many prefer, Pervasive Drive for Autonomy. PDA was identified in the UK in the 1980s by Elizabeth Newson and has recently received more attention in the US and Canada since PDA North America was established in March 2020. Currently PDA is widely understood as a profile of autism, with some recent studies linking it to ADHD as well, but more research needs to be done.

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.

Many families, educators and therapists have not heard of PDA, and it is often misunderstood and misdiagnosed. Since it is not a diagnosis in the DSM, many professionals do not have knowledge of it or understand it. We’ve created this guide in hopes that you will get a deeper understanding of what PDA is and how to support & accommodate people living with PDA.

We view PDA as a nervous system difference. We believe the strategies outlined in this document can be effective for anyone with a sensitive nervous system, not just PDA individuals.

Understanding PDA Individuals:

- High anxiety and 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
- Lower thresholds of tolerance for everyday tasks/activities
- Appearing sociable but lacking some understanding or skills in navigating situations or relationships
- Rewards and consequences feel like pressure, and generally backfire
- Difficulty complying with requests of others
- Enjoying pretending and role play
- Not appreciating hierarchy or age differences
- Seeming very interested in social interactions



Understanding PDA Individuals, cont.

- Sometimes acting very differently in different environments
- Appearing dominating and controlling, especially when feeling anxious
- Charismatic and engaging when they feel secure and in control
- Seeming callous, but feel deeply but may be oblivious of their impact on others
- Sensory differences
- Lack of Interoceptive awareness
- 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
- Often does not mind eye contact
- Behavior is communication
- Many PDAers have adaptive social skills with blind spots
- Enjoy spontaneity
- Dislike most routine
- Rewards, including praise, can feel threatening
- PDAers can be unorthodox and imaginative
- May have expressive empathy
- Triggers can be both predictable and unpredictable

Key factors to understand about PDA:

- PDA is not ODD and is often misdiagnosed
- Not all demand avoidance is PDA
- PDA is currently not a stand-alone diagnosis, nor is it proven to be a side effect of executive dysfunction or broader unsupported autistic needs
- PDA people share similar characteristics but each person is an individual and it's not a one-size-fits-all approach
- Approaches rooted in behaviorism do not work for most PDAers and can make things worse (time outs, rewards and consequences, etc.)
- PDAers' sensitive nervous systems can easily go into fight, flight, fawn or freeze states
- PDA individuals frequently 'mask' to fit in or feel safe, 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"



Understanding PDA Individuals, cont.

What is considered a 'demand' for PDA?

Demands in life are everywhere and cumulative. Demands cause stress. Because of this, PDA people have fluctuating capacity. 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 incapacitating

Internal Demands:

- The need to eat
- The need to use the bathroom
- Illness
- The need to rest/sleep

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 include things like taking a shower, eating a meal, brushing teeth, reading a book, hobbies, answering a text or talking.



Understanding PDA Individuals, cont.

PDA individuals have highly sensitive nervous systems:

- In Dr. Stephen Porges's Polyvagal Theory, behavioral responses represent how a person's nervous system constantly regulates the body's response to threat
- Challenging behavior can be viewed as part of the evolutionary process to survive and thrive
- Survival instincts live in three underlying neurophysiological states: social engagement, defense (flight or fight) or life threat (shut down or freeze)
- Dr. Stephen Porges coined the term "neuroception". Neuroception is the body's subconscious surveillance of safety and threat in the environment
- PDA people have highly sensitive neuroception
- Highly sensitive neuroception can react when the body perceives threat, even when other people view the threat as being present
- Humans are wired for connection
- Fight, Flight and Freeze are generally underneath challenging behaviors

Polyvagal Theory and neuroception are better explained by Stephen Porges or Mona Delahooke

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

- Manipulating social situations to remain in control
- Refusal: "Saying NO," "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?

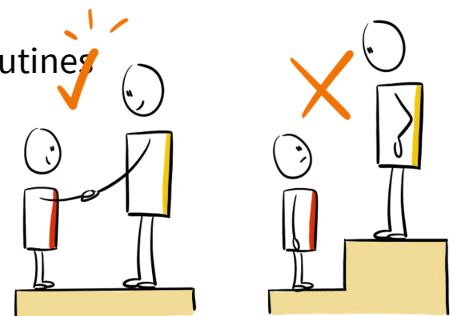
- Fight: Defensive verbally or physically
- Flight: Remove themselves from the situation, may elope
- Freeze: Shutdown - inability to fight, flight or fawn
- Fawning: Compulsive dominating or submitting (or alternating depending on setting!)
- Fibbing: Compulsive lying, confabulation
- Funster: Compulsive,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



Supporting PDA Individuals

Respect & connection are everything!

- Build trust by offering autonomy when possible
- Realize you must EARN their trust
- Focus on a genuine relationship
- Choose priorities
- Use indirect language including thinking aloud
- Have PDAers plan/decide their own schedule and routines
- Be spontaneous
- Use humor
- Listen to understand
- Collaborate - utilize partnerships
- Share tasks
- Show them you're equals, not above them
- Realize that **stress is cumulative** and there's likely no direct antecedent causing the behavior you're seeing
- Understand that emotions are contagious! If you are angry, they will become angry, if you are frustrated they will become frustrated, etc. Remember, it can work with positive emotions (calm, silly, happy) too!
- Co-regulation - lend them your calm nervous system
- Empathize with their intense feelings, but don't negate their feelings
- Allow PDAers to act in ways they feel most comfortable (don't push to mask or unmask - i.e. if a child needs to act like a dog to get out the door, let them!)
- Give them the 'deep why' behind your actions/needs for them. Help things make sense - they may not be able to act unless it makes sense
- Whatever the ask, **it has to be worth the energy and stress**
- Help them understand their internal life, thoughts, feelings and sensations
- Teach PDAers how to communicate about themselves and their needs to others
- Don't pressure PDA people, they have enough pressure on them





Supporting PDA Individuals, cont.

- Don't push your agenda
- Don't ignore them
- Challenging behavior is only a sign or signal that there is a problem - It is not the problem (*ref. Ross Greene*)
- Behavioral approaches (*including looking for antecedents*) don't work
- PDA individuals seem to go from 0 to 60 in a minute, but often their baseline is 50
- So many times, concerning behavior is caused by their trying to meet our needs and comply such as negotiating
- When supporting a PDA individual, every task has to be worth the stress and energy. You must try to always calculate this, as everything for PDAers 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...

- **Don't** 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

- Commenting aloud versus giving direct orders
- Sharing observations - "that snow looks cold"
- There is no correct or incorrect response to what is being said



Supporting PDA Individuals, cont.

Easy ways to use declarative language start with...

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

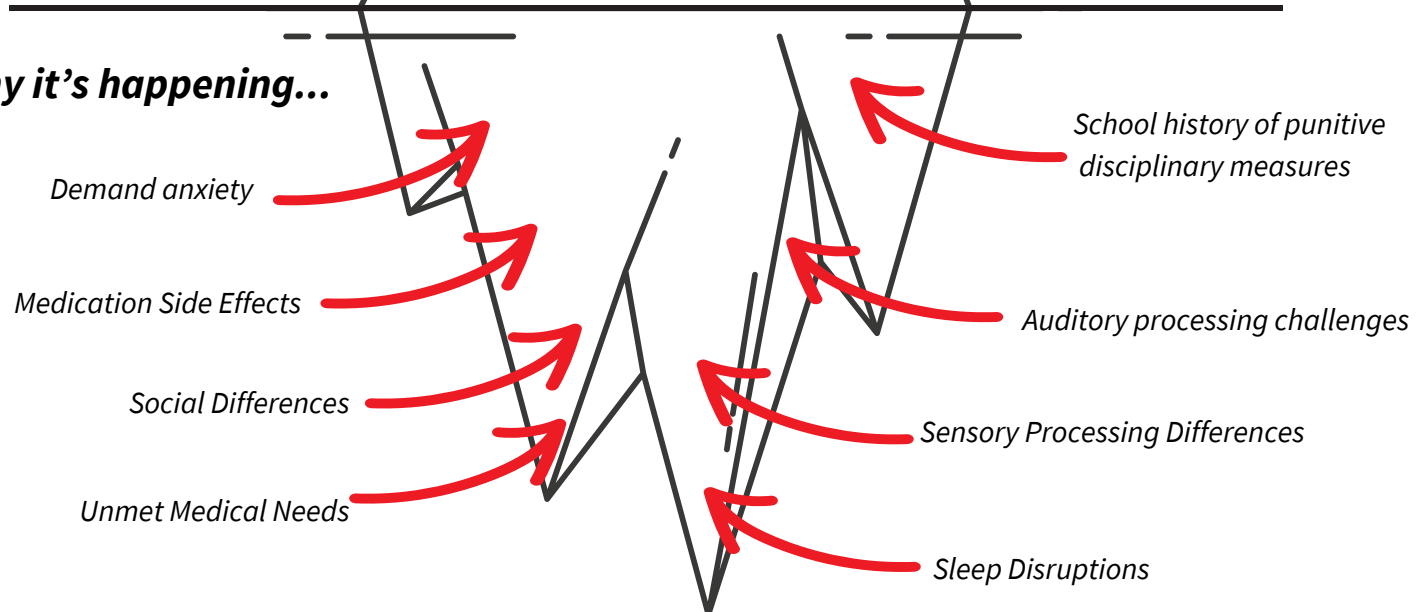
Tolerance VS Demand - looking under the iceberg:

Behavioral challenges are the “tip” of the iceberg, and the answers to helping individuals 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...



Why it's happening...





Supporting PDA Individuals, cont.

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

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


IN CONCLUSION:


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 with them



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 create resources for families to have a place to turn for support and guidance. We create trainings for professionals to better support and understand PDAers, and we highlight PDA voices, to help be better understood and supported. In short, our goal is to build a strong and vibrant community for this misunderstood population.

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

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