

# Demand Avoidance

Understanding and supporting the complexities of Demand Avoidance



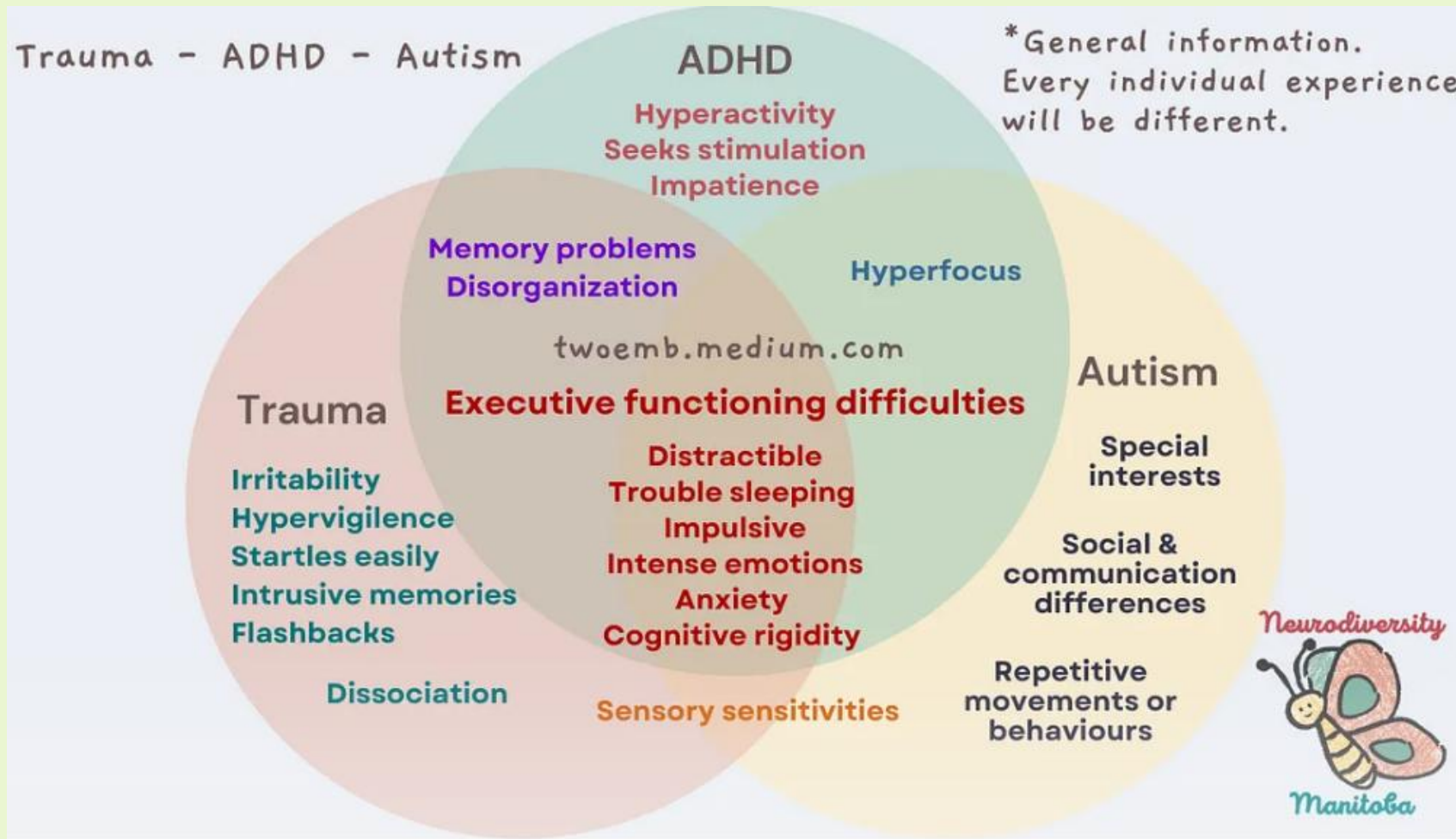
How many of these photos can you relate to?

Behaviour is always communication

# What is Demand Avoidance?

- ▶ **Everyone experiences 'demand avoidance'** (resistance to doing something that is requested or expected of you) sometimes. However, here we use demand avoidance to mean the characteristic of a persistent and marked resistance to 'the demands of everyday life', which may include essential demands such as eating and sleeping as well as expected demands such as going to school or work.
- ▶ Although demand avoidance is **widely acknowledged as a characteristic** experienced by and observed **in some autistic people** and potentially other neurodivergent, but not autistic, people, there is very little research into it and the research that does exist is generally of a low quality. Because of this, many aspects of demand avoidance - including how it is best defined and identified; how common it is; why it happens; and support strategies for someone experiencing it - are under-researched and often contested.
- ▶ The National Autistic Society regularly updates its webpage on [Demand Avoidance](#).
- ▶ Demand Avoidance is **sometimes known as Pathological/Extreme Demand Avoidance or P/EDA**
- ▶ <https://www.somerset.gov.uk/children-families-and-education/the-local-offer/education/autism-and-adhd-pathway/position-statement-on-demand-avoidance/>

# Cooccurrence and Anxiety



# Pathological Demand Avoidance (PDA)

- ▶ **The Somerset Demand Avoidance Policy**
- ▶ We believe that every young person in Somerset should have their individual needs understood, including when accessing an autism assessment. Assessment services in Somerset are focussed on understanding children and young people, rather than just a diagnosis. This may include a description of demand avoidant behaviours that the young person engages in, and an attempt to understand why they feel the need to do so.
- ▶ Services in Somerset are only able to give diagnoses that are listed in specific classification manuals ([ICD-11](#) or [DSM-V](#)). **In short, P/EDA is not currently a recognised diagnosis in the United Kingdom.** However, we recognise that some young people will act in ways that help them to avoid demands. This includes some young people who meet the criteria for a diagnosis of autism.
- ▶ This position will be reviewed and updated in line with current and emerging evidence and NICE guidance. We will continue to follow our protocol and guidelines when assessing for a possible Autism Spectrum Conditions.
- ▶ Statement Updated November 2023
- ▶ <https://www.somerset.gov.uk/children-families-and-education/the-local-offer/education/autism-and-adhd-pathway/position-statement-on-demand-avoidance/>

# What is the Impact on the Child?



- ▶ Difficulty getting to sleep, staying asleep and getting up
- ▶ Short and long-term effects from anxiety and associated symptoms
- ▶ Difficulty with self-care tasks such as personal hygiene, eating and household chores
- ▶ Experiencing panic attacks, intense emotional distress and/or difficulty regulating emotion
- ▶ Difficulties in friendships or other social relationships
- ▶ Inability to attend education or employment due to distress and/or burnout, which may result in exclusion or termination.

# What is the Impact on you as Parents?

- ▶ Distress from witnessing their child in extreme distress
- ▶ Challenges and exhaustion from trying to find effective ways to reduce, disguise or remove demands and support the person
- ▶ Stress and frustration from trying to access or implement appropriate support in areas such as diagnosis, education, mental health and social care



# What are Demands?



# Our Usual Behaviour Strategies Aren't Working

- ▶ Time count downs
- ▶ Time out
- ▶ Short, sharp instructions
- ▶ Rigorous and consistent routine
- ▶ Being assertive, taking control when they are feeling unsafe
- ▶ Tightening of boundaries

All of these strategies are causing the child more dysregulation

# Why aren't our Usual Strategies Working?

- ▶ They sense a threat
- ▶ High anxiety - demand avoidance is anxiety driven
- ▶ Demands take away their freedom
- ▶ If the child feels that their freedom or control are lost behaviours will escalate
- ▶ They feel a deep sense of protection keeping control
- ▶ When we feel anxious we will seek to avoid things and may panic when asked to step out of our comfort zone

# Which Strategies do Work?

- ▶ Reducing, removing, managing and disguising demands - reduce the cognitive overload
- ▶ Allow take up time - consider their window of tolerance
- ▶ A collaborative approach that flattens hierarchies
- ▶ A coordinated approach to support
- ▶ Indirect communication styles
- ▶ Use their interests
- ▶ Give choices
- ▶ Use humour
- ▶ Use distraction
- ▶ Validation, seek to understand - pink cup analogy
- ▶ Avoid and understand potential triggers - eye contact, body language
- ▶ Remove any spectators to a distressing situation - give space, no shaming
- ▶ Sensory regulation and creating a sensory environment that works for them
- ▶ Therapy, counselling, mindfulness and meditation - what happened to you?

# 5 Golden Rules

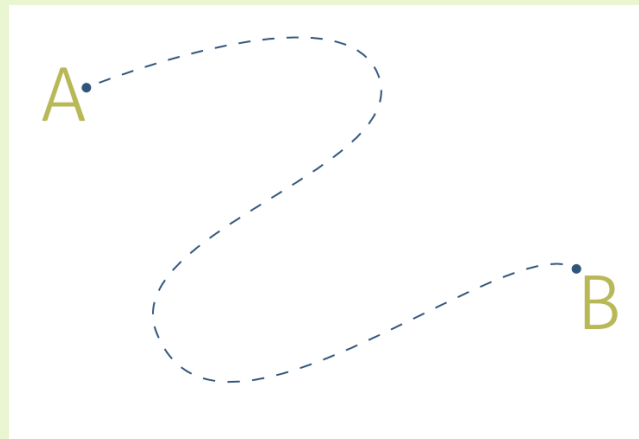
- ▶ Think Ahead
  - ▶ Give the child advanced notice
  - ▶ Monitor the child's stress levels and scale back demands
  - ▶ Create space
  - ▶ Keep calm
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- ▶ <https://www.pdasociety.org.uk/wp-content/uploads/2020/01/Positive-PDA-booklet.pdf>

# What about Boundaries?

- ▶ It doesn't mean removing boundaries
- ▶ It means meeting them where they are
- ▶ Getting on their level
- ▶ Attuning with them
- ▶ Offering respectful relationships - can't cooperate if there isn't a relationship
- ▶ Authority figures can be triggering - show your human side, be less threatening
- ▶ Really consider the demands being placed on a child - which are necessary parts of the routine and day - what can go?
- ▶ Establish pinch points
  - ▶ what is triggering them?
  - ▶ How do we overcome it?
  - ▶ How do we create intrinsic value to the activity in hand?
  - ▶ What is making the child feel unsafe?

# What about times where they just have to follow a demand?

- ▶ Attempting to get the child to comply - doesn't work
- ▶ You're selling a product
- ▶ Be an entrepreneur rather than authoritarian
- ▶ Offer inspiration over instruction
- ▶ Now and next provides some level of intrinsic value for those tasks that just have to happen - nappy changing, handwriting, getting dressed
- ▶ The child needs to understand the intrinsic value of doing something.
  - ▶ What's the point?
  - ▶ Why does it matter to me?
  - ▶ What's in it for me?



# Empathy is Especially Important

- ▶ Supporting a child with demand avoidant behaviours can be triggering for adults
- ▶ Be kind to yourself
- ▶ Learn your own bias and challenge it
- ▶ Know your limits - change of face
- ▶ Be mindful of expressions and body language
- ▶ Offer that same empathy to the child
  - ▶ I know it's hard for you
  - ▶ I know that it's triggering
- ▶ You can't fake it, they will know!
- ▶ The children have learnt to be highly vigilant to protect themselves from threats. You have to believe and understand demand avoidance and truly accept that it's not just naughty behaviour

# Rewards

- ▶ Remaining in control is their greatest reward
- ▶ Intrinsic motivation is key
- ▶ Demand avoidance can't be incentivised by a reward but the child will no doubt enjoy accepting a reward once a task has been completed, everyone likes praise!

# Scenario - I want another biscuit...

- ▶ No, they've all gone
- ▶ You can't have any more
- ▶ I'm really sorry but I can't magic up any more biscuits
- ▶ They are finished
- ▶ I don't know what you want me to do about this
- ▶ You need to stop shouting at me now
- ▶ I can see that you're feeling really sad right now
- ▶ It can be really hard when things finish
- ▶ I don't have any more biscuits, I wonder if there's something that could take your mind off it
- ▶ I wonder if there's anything else in your lunchbox that you could try
- ▶ I wonder if playing with the Lego would help
- ▶ I can't see how we can make this worry tummy go away, can you?

# Indirect and Direct Language

## ▶ Indirect

- ▶ “I wonder if we can...”
- ▶ “Let’s see if we can make something...”
- ▶ “I can’t see how to make this work...”
- ▶ “Shall we see if we can beat the clock...”
- ▶ “Maybe we could investigate...”
- ▶ “Who do you want to help us today...”

## ▶ Direct

- ▶ “It’s time for you to...”
- ▶ “You’ve got to...”
- ▶ “You need to...”
- ▶ “You must...”

Holding the boundary but differently

# How could we respond in these moments?

- ▶ Child is refusing to wash their hands
  - ▶ Child is refusing to eat their dinner
  - ▶ Child is refusing to put their clothes on
  - ▶ Child is refusing to come into the kitchen for their breakfast
  - ▶ Child is refusing to finish playing with their lego
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- ▶ First, seek to understand them. Why are they feeling threatened?
  - ▶ Secondly, validate them. Attune to their emotion.
  - ▶ Then, respond with indirect language.

# Yes or No?

- ▶ You need to put that down and follow me
- ▶ I wonder whether you'd like to try some carrots
- ▶ Sometimes we have to do things that we don't want to do
- ▶ I can see that you're feeling really sad
- ▶ It's time for us to go home now
- ▶ I wonder if we can throw the ball more than 5 times
- ▶ You've got to wash your hands after using the toilet
- ▶ Who do you want to help you with your shoes?
- ▶ You need to take off your coat.
- ▶ Maybe we could investigate why the cat isn't coming out to play.
- ▶ You must eat your vegetables first.
- ▶ Let's see if we can make something for Nanny because I know you're missing her.
- ▶ I can't see how to make this work, can you?
- ▶ Shall we see if we can beat the clock?

Remember...

YOU CAN'T CONTROL  
OTHER PEOPLE.  
YOU CAN ONLY CONTROL  
YOUR REACTIONS  
TO THEM.

*be kind to yourself.*  
BE PROUD OF YOURSELF.  
*because you matter.*  
WHAT YOU DO MATTERS.  
*you make*  
A DIFFERENCE.