

A-Z of Demands

Pathological Demand Avoidance (PDA) is a profile on the autism spectrum. One of the key features of PDA is resisting and avoiding ordinary demands and expectations of life to an extreme extent, not just typically difficult or unpleasant things but ordinary everyday things. This is not a choice and is lifelong.

PDA demand avoidance can include: distracting or negotiating with the person making the demand; excusing oneself; becoming physically incapacitated; withdrawing into fantasy; emotional and physical outbursts and more, making everyday tasks and activities incredibly difficult to do.

Exceptionally high levels of anxiety can accompany PDA demand avoidance as well as a need for control, freedom and autonomy.

The following notes highlight some of the demands which can impact on day-to-day life with PDA. All individuals are unique and this is by no means a complete list as demands are many and varied, but I hope it helps to illustrate how all-encompassing PDA is and how quickly demands can accumulate.

A is for Agreements

Agreements can carry such a weight of expectation and pressure to follow through with, that they become demands.

Sometimes, during demand avoidance negotiations, deals or promises are made to do a task at a later time but when it comes to fulfilling the agreement, greater demand avoidance is triggered due to the additional expectation felt.

A-Z of Demands

B is for Brushing teeth

The pressure associated with teeth brushing can feel immense. The fact that it **MUST** be done can make this task a huge demand.

Even if having clean teeth is desired, the lack of control over having no other option but to brush them to achieve this can cause considerable anxiety.

Knowing why regular brushing is necessary may only add to the pressure too and make it even more difficult to achieve. Likewise receiving praise for achieving it may increase the pressure to do it again.

In addition to this, sensory difficulties and not being able to tolerate the feel of brushing or the taste of toothpaste can also contribute towards avoidance.

C is for Clothing

Demands associated with clothing can include: wearing clothes, physically getting dressed and wearing appropriate clothing for the situation and weather.

The fact that wearing clothes and getting dressed are necessary tasks and not a choice can make them extremely difficult demands to begin with. Having to get dressed by a certain time and any expectations to wear particular or appropriate clothing can massively increase anxiety and the pressure felt, making them harder still. Sometimes, wearing clothing that isn't seasonal or is somehow different to what is expected is necessary to be able to manage the demand and/or someone may need to physically help with dressing because the demand to do it is too great. Other times, getting dressed or certain clothing may need to be avoided entirely.

In addition to this, sensory difficulties can also contribute towards avoidance (this can also be changeable, depending on how much sensory overload is being experienced).

A-Z of Demands

D is for Decisions

Sometimes knowing a decision HAS to be made makes it a demand.

Choices can be helpful in minimising anxiety and providing a sense of control but sometimes making a decision is a demand in itself due to the overwhelming feeling of HAVING to make a choice. This can cross over with other demands, triggering further avoidance, or can be a stand-alone demand, making some everyday decisions or choices, even for pleasant things, incredibly difficult, if not impossible. The anxiety which can accompany this demand can be immense.

E is for Eating

The very fact that eating is an essential part of life and not a choice can make it a demand at times.

Following rules around eating or eating at a time or place set by someone else or food someone else has chosen can also remove control and turn eating into a demand.

At its most extreme, avoidance can mean not eating when hungry or declining offers of food in a variety of ways. Other behaviours associated with this demand can include: only eating a limited number of chosen foods, eating at unconventional times, not eating with others, using a distraction such as a screen while eating, and having various other specific requirements around eating and food. These all provide a sense of control around the demand and can help to reduce associated anxiety greatly and make eating more achievable.

In addition to this, sensory difficulties and/or fear of trying new things due to an intolerance of uncertainty can also contribute towards avoidance.

A-Z of Demands

F is for Following instructions

Instructions tell you how to do something and following them can be a huge demand as it removes personal autonomy.

The loss of control felt from being given instructions to follow can be so great that sometimes such tasks are avoided completely. Other times the method is altered or changed entirely in order to feel a sense of control over the demand and be able to carry out the task. Role-playing as a character while following instructions can also make it more manageable as the demand is transferred onto the character and away from the individual.

In addition to this, difficulties with language processing and working memory can also make following instructions confusing and overwhelming.

G is for Getting ready

Getting ready in the morning typically requires lots of demands to be met. These can all mount up to make it an enormous process, filled with anxiety and demand avoidance.

The same can be true for getting ready for bed too.

Typical demands associated with getting ready in the morning and leaving the house can include: waking up, getting out of bed, getting dressed, toileting (and washing hands), eating breakfast, brushing teeth, brushing hair, putting shoes on, maybe putting coat on and finally, leaving the house. Each demand can cause a huge amount of pressure and anxiety due to them being necessary daily tasks and not a choice. Time pressures can also mount up when there is a certain time to be ready by and every demand can trigger demand avoidance. Getting ready can be overwhelming and as overload increases, demand avoidance can start to escalate rapidly making getting ready an incredibly difficult and exhausting process. Sometimes fully achieving every demand is not possible and some may be avoided entirely.

A-Z of Demands

H is for Housekeeping

Housekeeping tasks such as tidying and cleaning up can be demands which lots of people dislike and choose to avoid. In PDA though, the avoidance is NOT a choice and it's the pressure to do the tasks rather than a dislike of them that fuels the avoidance.

The demand to tidy things away or clean up can be overwhelming because aside from the fact that they're necessary tasks in life or that someone may have asked that it be done (two factors which remove control and can instantly trigger avoidance), great emphasis is generally placed on doing them in order to be responsible and helpful, both of which are expectations which can carry a great weight of pressure. Pressure from all of these factors can trigger demand avoidance, even if the individual wants to help or wants their surroundings to be tidy and clean.

I is for Independence

A PDAer needs independence in terms of personal autonomy and to feel in control, but doing tasks independently can sometimes be a demand.

Doing a task independently can be a stand-alone demand (the very fact that something HAS to be done by the individual to achieve a desired outcome can remove a sense of control and choice and trigger demand avoidance). It can also overlap into other demands too. Perceiving or hearing that something can or should be done independently can create an immense feeling of pressure on top of the pressure already felt from another demand, intensifying anxiety massively. Either way, doing things independently can be such a huge demand and avoidance can lead to physically not being able to do the task and needing someone else to either assist in some way or do it for the individual, even things which have been done independently before. This can wrongly be perceived by others as laziness. It is not laziness. It is an incapacity due to a hidden disability.

A-Z of Demands

J is for Job

Having a job can be a huge demand. The number of demands involved in a day's work can quickly mount up too.

PDA is lifelong and demand avoidance can make working in a conventional way incredibly difficult or even impossible. Demands can be anything which remove a sense of control and, typically, jobs involve many such demands which can cause anxiety and trigger demand avoidance. It can be a demand to go to work at a set time for example or to do what is expected whilst there. The thought of having a job when she is an adult already triggers avoidance in my child. Even the prospect of doing something she loves as a job is a demand which fills her with dread and causes her anxiety because it would HAVE to be done and therefore remove a sense of choice and control. She still has ambitions and talents she wants to develop and share but will need flexibility, support and to feel in control of what, where, when and how she does that.

K is for Keeping clean

Washing to keep clean can be an extremely challenging demand.

Like other self-care tasks, keeping clean is a necessary part of life and the pressure to wash hands, bathe, shower or wash hair can feel immense because of this. The loss of control and anxiety associated with this demand can be so great that demand avoidance can make washing and keeping clean incredibly difficult to achieve.

It can sometimes even prevent an individual from being able to wash at all for a period of time.

In addition to this, sensory difficulties can also contribute towards avoidance.

A-Z of Demands

L is for Learning

Any learning, which is outside of the individual's control, can be a massive demand. The need for control in PDA can trigger extreme anxiety under such circumstances and learning can be significantly hindered.

Autonomy in learning is essential as, without it, engaging with learning can be incredibly difficult and anxiety can lead to explosive, disruptive or shutdown behaviour. Sometimes an individual can mask their anxiety and demand avoidance or appear on the surface to do just enough to get by so difficulties go under the radar, but learning can be limited. Work, homework, school or other educational settings may even be avoided entirely. It is therefore vital that educators and supporting adults understand PDA and the needs of the individual and work collaboratively, both together and with the individual to create personalised learning experiences, while adopting a flexible, creative and indirect manner and providing as much autonomy as possible to minimise anxiety and maximise learning opportunities.

M is for Manners

The social expectation to have good manners can cause a significant amount of pressure and make them a huge demand.

The weight of expectation to say 'please' or 'thank you' or use other socially acceptable manners can trigger demand avoidance. The avoidance of this demand is often viewed as rude, with the individual's actions misinterpreted as ungrateful or disrespectful. Avoidance cannot be helped and isn't a reflection of respect or gratitude and the insistence of such manners can actually increase anxiety, escalate avoidance and make the demand even harder to overcome.

A-Z of Demands

N is for **No you can't...**

Being told what NOT to do can be a massive demand because it puts someone else in control.

As a key feature of PDA is an anxiety related need for control, this demand can be unbearable.

The loss of control felt when someone says 'no' to something which is important to an individual with PDA can cause immense anxiety. As well as demand avoidance, this can trigger a great deal of distress. Sometimes this distress can manifest as angry or violent behaviour. The overload from the situation may even trigger a type of panic attack known as a meltdown.

O is for **Own self-imposed expectations**

Demands aren't only limited to other people's requests or expectations.

An individual's own self-imposed expectations can turn into demands as well.

It can be incredibly hard (or at times impossible) for an individual with PDA to do some of the things they want to do. They may have chosen or planned to do something but the weight of expectation to do what has been committed to can turn it into a demand, triggering anxiety and demand avoidance. All of the necessary actions (demands) involved in doing something they want to do can be overwhelming too.

A-Z of Demands

P is for Praise & Perceived demands

When an expectation to do something is perceived it can become a demand. These demands aren't directly given to an individual but are perceived as demands nonetheless. Praise can turn something into a perceived demand if the expectation to do what was praised again, is perceived.

Receiving praise for doing something can highlight 'compliance' and can result in the perceived demand to comply again. If the praise is about how well something is done, the perceived demand can be to do it as well again. This can make receiving praise uncomfortable and pressurised for some. Others, though, can enjoy or need a lot of praise and positive acknowledgment, so long as no future expectations are perceived along with it. Awareness of all sorts of expectations can result in many perceived demands being experienced throughout any given day and it's important to recognise the impact this will have on anxiety levels, behaviours and tolerance of other direct or perceived demands.

Q is for Questions

Answering a direct question and responding to a question in a way that might be expected can be demands.

Sometimes the weight of expectation to answer a question can make it a very difficult demand to meet. This can be true of verbal or written questions and demand avoidance can make responding or responding relevantly very difficult indeed. In addition to this, extra processing time can sometimes be needed before a response can be given. Being pushed for a response or having the question repeated during this necessary processing time can be overwhelming. This can escalate avoidance and anxiety, making it even harder to respond.

A-Z of Demands

R is for Rules

Rules can be a huge demand. They can remove autonomy and a sense of control and any expectations or pressure to follow them can increase anxiety and demand avoidance.

Direct rules can cause a great deal of anxiety and demand avoidance and can be incredibly difficult to follow.

Limiting the number of day-to-day ground-rules for a child with PDA, to only essential ones, may be necessary to minimise anxiety.

In addition to demand avoidance, an individual with PDA may not be able to apply certain rules to themselves, yet can feel very strongly that others follow them and can become highly anxious if they don't.

S is for Suggestions

Suggestions and advice from others can be perceived as demands.

Even if someone suggests doing an enjoyable activity or something the individual would like to do, the fact that someone else suggested it can make it incredibly difficult, sometimes impossible, to accept. Accepting the advice or suggestion can give control to the other person and the anxiety felt from this potential loss of control can trigger demand avoidance.

A-Z of Demands

T is for Transitions & Timetables

Transitions and timetables imposed by others can be demands which can trigger extreme anxiety and avoidance.

Transitioning from one thing or place to another, like stopping something or leaving somewhere, when someone else says to, can feel like control is lost and given to the other person.

This can trigger demand avoidance which can make imposed transitions very challenging.

Having to do things at set times, according to a timetable, can also remove a sense of control and can trigger demand avoidance. A more free-flowing and flexible approach to daily activities may be necessary in order to increase a sense of control to minimise anxiety and maximise what can be achieved.

U is for Using the toilet

Using the toilet can be a demand due to the fact that it is a bodily need rather than a choice.

The demand to do something because of a bodily need can cause anxiety and demand avoidance just like any other direct or perceived demand because the need is out of the individual's control. This can make using the toilet very difficult and everything else associated with the demand (undressing, cleaning, dressing and washing hands) can be additional demands which may require extra support.

A-Z of Demands

V is for behaVe

A request or expectation to behave in a particular way can be a huge demand. It can remove autonomy and massively increase anxiety.

Demand avoidance can lead to the opposite behaviour than is expected or desired. It's important to remember that the avoidance is NOT a choice, nor is it a reflection of upbringing or how the individual wants to behave. Some individuals mask anxiety and demand avoidance in certain settings or with certain people however, to fit in. The impact of demands, whilst masking though, is just as severe, only it is delayed until the individual is away from the setting or people where masking occurs. Once away, the built-up anxiety is released and the effects of demands and masking become visible. This increases demand avoidance elsewhere and emotional or physical outbursts or shutdowns can also be a result.

W is for Waiting

Having to wait can be a demand which can cause huge amounts of anxiety and can be very difficult to do.

Intolerance of uncertainty may play a part in this if the waiting time is unknown or not understood. However, waiting can still feel completely out of an individual's control even if the waiting time is known, due to the fact it HAS to be done. This loss of control can increase anxiety and lead to emotional dysregulation. Demand avoidance can present as the individual tries to regain control over the situation in a bid to feel safe.

A-Z of Demands

X is for please do X

Being told what to do is an example of a direct demand. It can remove choice and control and increase anxiety massively.

Typically, children are frequently told what to do on a daily basis and for PDAers the mounting up of these direct demands can be a constant source of extreme anxiety and demand avoidance. A less conventional type of adult/child relationship, whereby both parties collaborate on outcomes and the adult is flexible, can help to facilitate the need for control which can minimise anxiety and demand avoidance.

Y is for Yesterday I could...

What could be done yesterday, may trigger demand avoidance today.

Anxiety levels and tolerance of demands fluctuate all the time, meaning demand avoidance can vary from day to day (or week to week). Some days certain demands may be able to be met while on others they may not. In addition to this, what could be done yesterday may trigger demand avoidance today due to the perceived expectation to be able to do it again. This variability can be incredibly frustrating and confusing.

A-Z of Demands

Z is for Zzz

Sleep can be a huge demand, resulting in sleep avoidance. Going to sleep can be incredibly difficult to do and bedtimes can be a very anxious and stressful time.

The fact that it's something that must happen every day and is a bodily need rather than a choice can make sleep a massive demand and there's so much that can feel out of an individual's control around sleep including: dreams; the day coming to an end; the way falling asleep feels; the time it can take; that doing it cannot be controlled and not being in control while asleep. Not having control of when and where sleep happens can also be a source of anxiety. Avoidance can be extreme and can delay sleep by a considerable amount of time each day. This can impact on quality of sleep and wellbeing.

Also available on the Notes on PDA blog is an A-Z of PDA Support Strategies in which we share the approaches that help our child (who has a PDA profile). Please see notesonpda.wordpress.com for the link.

More information about PDA and advice for people living and working with PDA, including helpful approaches and first-hand insight from PDA individuals, can be found on the PDA Society website: www.pdasociety.org.uk

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