Simple strategies for supporting children with Pathological Demand Avoidance at school

Zoe Syson and
Dr Emma Gore Langton

Contents

Acknowledgements

Many thanks go to the parents and school staff who took part in this research. We are also very grateful to Joe Windsor, who designed this booklet, and to Andy Whittle for his illustrations.

Welcome

Pathological Demand Avoidance (PDA) was first described by Professor Elizabeth Newson in the 1980s as a pervasive developmental disorder. Today the National Autistic Society recognises PDA as part of the autism spectrum, but in some regions PDA does not yet have formal diagnostic status.

Limited research has meant that a very vulnerable and highly complex group of children often diagnosed with ASD or other related conditions have been misunderstood as naughty or disruptive.

At school these children often struggle to reach their potential because of their need to be in control. The invisible barrier of anxiety and avoidance is often forgotten and the child appears to be choosing not to engage when in fact they don't know how to overcome these feelings on their own.

The approaches and strategies in this booklet come from research conducted by Dr Emma Gore Langton, Educational Psychologist. Emma interviewed the parents and teaching staff of nine children with PDA, ranging from Reception to Year 6. Parents and teaching staff spoke in great detail about the strategies they found most helpful, so that they could be passed on to others. All quotations come directly from the participants.

This booklet has been written with Zoe Syson. Zoe is the parent of a child with PDA. She is also a teacher with experience of working in both mainstream and specialist schools. Zoe has recently gained a Postgraduate Certificate in Autism from Sheffield Hallam University.

We've packed this booklet full of strategies which are simple and free. Some may take a bit of practice, or a shift in how we think, but we hope you will find them useful.

What's different about PDA?

Parents and teachers tell us that it's vital to understand how PDA differs from more typical autism spectrum conditions. This is because strategies which work well for children with autism can make things worse for children with PDA.

AVOIDANCE of ordinary demands is the primary and most debilitating characteristic of PDA. It's driven by the child's uncontrolled ANXIETY which can feel like a PANIC ATTACK. Children will often respond by saying 'No' to what they're asked or told to do, even if it's something they actually enjoy. If saying 'No' doesn't work they may use the following tactics to avoid demands:

Delaying	Distracting	Negotiating
Charming	Making excuses	Falling to the ground
Shouting	Explosive behaviour	

You've probably noticed that several of these avoidance techniques require adequate social and language skills. Children with PDA may appear to be verbally competent, but may understand less than we think. Although they may be highly sociable, they usually struggle to understand where they fit in the social hierarchy (e.g. that adults have more authority than children), and their need to be in control can mean that their peer relationships run into trouble.

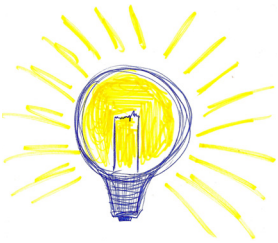
The other key area of difference is that children with PDA are often highly skilled when it comes to pretend play. They may become easily engrossed in fantasy to the point where they 'become' certain characters and confuse pretending with reality. Some research has described this as a coping mechanism because it is a barrier to outside demands.

Because of these differences with more typical autism, children with PDA need a different set of strategies to support them.

Five golden rules

1 Think ahead

Look at the day and week ahead, to anticipate what might be tricky for the child. Identifying the predictable triggers will mean you can plan strategies in advance.



"There has always been a particular problem with things like sports days. This sports day was absolutely fine as she didn't have to join in if she didn't want to, and the TA sat with her. So they're aware of things that cause her particular anxieties, and do what they can to prevent anything happening."

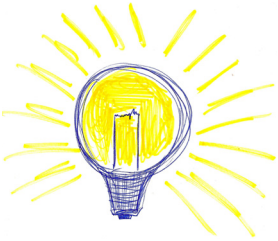
Parent of KS2 child

It is important to develop a strong relationship with a child who has high anxiety. There is a suitcase template on page 27. Spend time with the child filling a suitcase with their favourite characters and activities. What you are actually doing is getting to know the child and their interests. The more you understand them the easier it will be to distract them from potential crisis and you will feel confident in how best to diffuse a situation. The teacher can fill their own suitcase with strategies and reminders of how best to help a specific child to reduce their anxiety and access learning.

For older children who have some insight into their difficulties, you might like to work together to jointly complete the 'All about me' profile on page 25; this allows you and the child to communicate key messages to all staff in an easy-to-use format.

2 Give the child advance notice

Children with PDA find it helpful to know what is going to happen, as this gives them a sense of being in control, as well as allowing them processing time.



"I've done a timetable for her that's equivalent to my classroom timetable, which is given to her and her parents every Monday morning. Anything that's in red means that I'm actually not teaching it; or we're not in our own classroom i.e. or we have visitors in, and underneath, any changes will affect her on that day. I speak to her about any forthcoming events well in advance, and tell her exactly how it's going to be different."

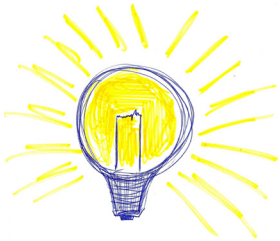
Teacher of KS2 child

For some children, displaying information in a visual format can create a sense of independence and choice which reduces anxiety e.g. visual timetables can be made with the child and used to help the child understand what is happening. It is important to use these in a flexible and non-confrontational way, and that they are created and referred to *with* the child, rather than being done 'to' the child. Children may like to draw their own symbols to use:

3 Monitor the child's stress levels & scale back demands

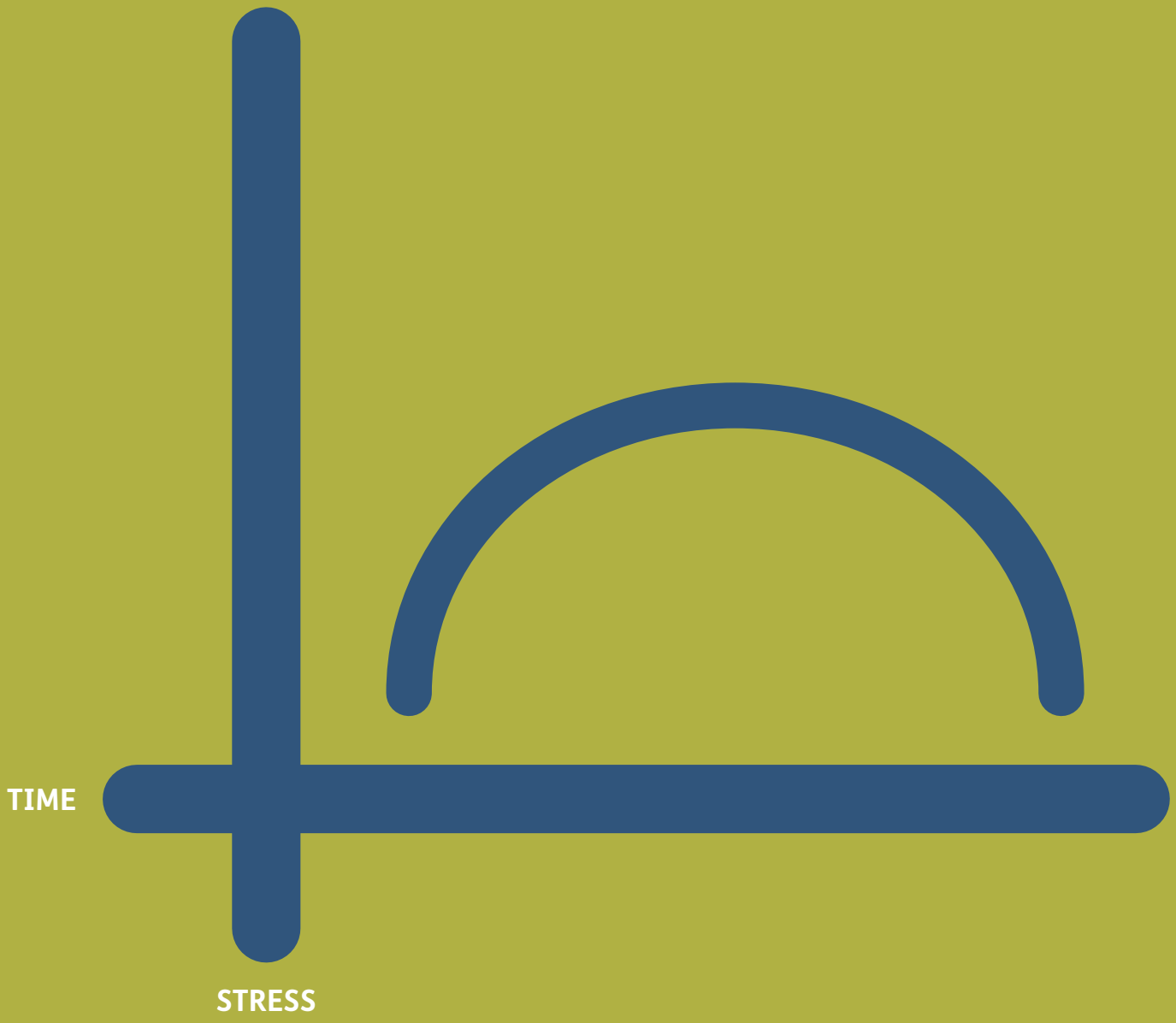
The mood and behaviour of children with PDA can change very quickly. It is important to look out for signs of increased anxiety, which can be reduced by decreasing demands. Speak to parents for clues about the first tell-tale signs that the child is struggling. It's best if all staff (e.g. playground supervisors, dinner staff) are aware of these signs, so they can feed back to the child's key person. Teaching assistants can be particularly helpful as they can step back when the child is coping well, but be available nearby to intervene if the child becomes anxious. At the first signs of stress, it's a good idea to scale back the demands on the child.

As the child gets older, it's important to encourage them to begin to identify their own stress levels and what they need, and to teach them the skills to communicate this. A feelings board, like the one on page 26, is a quick and useful aid to this. This can be available to children on the wall, and they can place their photo or name by the feeling which best matches their mood, and choose what they need.



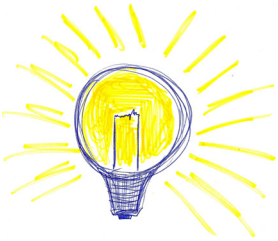
"They're in ability groups. She could have easily been in the top group, but was finding that too stressful, even though she has the ability, so we moved her to the middle group, which she's done really well in. And that's just being a bit flexible, if it meets her needs emotionally, then that's fine, because she's not feeling as much pressure."

Head teacher, KS1 child


TIME
STRESS

4 Create space

Children with PDA find it hard to regulate their feelings.
Make sure there's space in the classroom or school where they can go to feel calm.



"They've made her a little area with a rainbow canopy, and she often goes in there first thing when she gets to school."

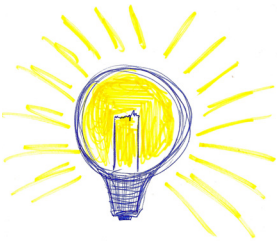
Parent of KS1 child

"I think having a table to herself has helped"

Teacher of KS2 child

5 Keep calm!

When children with PDA panic, they need the adults around them to stay calm. We must regulate ourselves first, so that we can then help the child to regulate their anxiety.

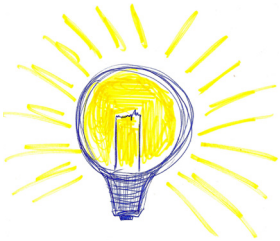


"The biggest thing I would say to anybody about PDA is 'Keep calm'. If you get stressed and are getting more anxious, the whole thing is like igniting dynamite. You just need to keep it calm..."

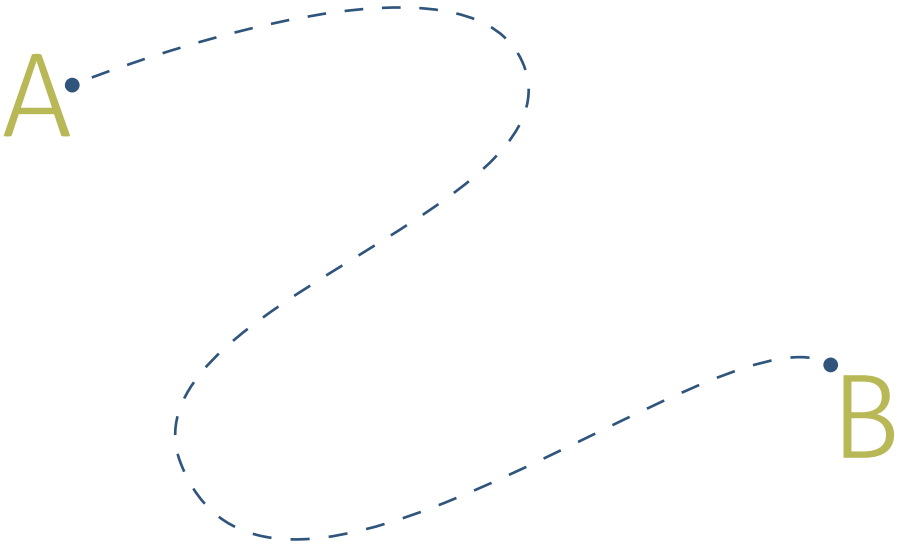
Parent of KS1 child

How to avoid demand avoidance

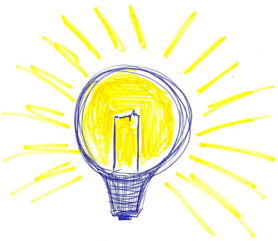
In a typical school day the level of demands on children can feel overwhelming. Here are some ways parents and school staff have found to disguise the demands they are making, so as to reduce the child's anxiety. Although these strategies can feel a bit long winded, overall they save time and children engage far better.



It's never a direct route from A to B, so be prepared with strategies and resources to gently lead the child to where you want them.



1 Use indirect language



"Really it's just how somebody asks him to do something; if he sees it as 'We need to go and do our reading now' he will refuse to do it, but if it's 'Oh it's our discovery time today, we're going to do some reading, would you like to choose a book from these two?' then he's more compliant."

Parent of KS1 child

Here are some handy sentence starters:

"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..."

Try to avoid saying:

"It's time for you to..."

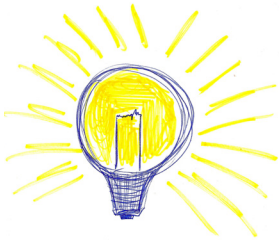
"You've got to..."

"You need to..."

"You must..."

2 Allow take up time

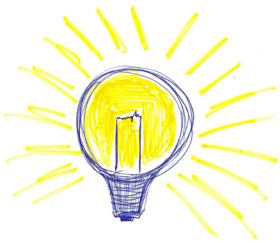
Plant the seed of what you would like to happen at the start of the session, but don't expect it to happen straight away.



"If they're given a task, sometimes what she likes to do is to watch, and then she's fine, but if you were to, as you would with some children, chivvy them along, she'd become entrenched... Whereas if you go 'That's fine, you just watch', the reality is she's an interested, bright child, and actually she can't resist wanting to join in...You let her come round herself."

SENCO of KS2 child

3 Use the child's interests



"Anything he shows an interest in, I just jump on it and think 'How can we use this..? He went through a stage of really liking the Crystal Maze, so we would just pretend that it was something to do with Crystal Maze and then he'd do it. So that was something quite fun and exciting for him. He'd do it then."

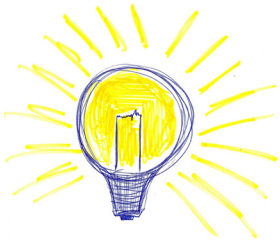
Parent of KS1 child

Using characters of interest can help depersonalise demands, as you are not personally asking them to do something. For example, if the child loves Thomas the Tank Engine or Star Wars, try to find a character voice you can use to make requests. Or you could find a toy or puppet to represent the character, saying:

"The Fat Controller says these are the station rules"

"Luke Skywalker would like us to try to work this out to save the galaxy!"

This can take a bit of practice, but drama and role play appeal to many children with PDA. You can also use the child's momentary actions or focus to transition them into an activity; for example, if a child is drawing a knight, you could sketch a little picture at the top of the worksheet you'd like the child to do, saying 'Look, your knight is here to watch you do this and then we can finish your big picture'.

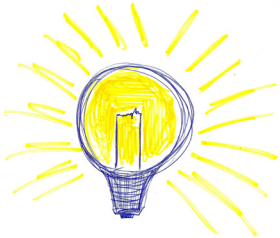


"We often use a toy he's brought in, using role play and acting out the character, so delivering requests through the character. So I'll pretend to be the characters and use their voices."

Teaching Assistant of KS1 child

4 Give the child choices

Giving simple choices will help the day run smoothly. This gives children a sense of having some control, while ensuring that you keep the key requirement firm.

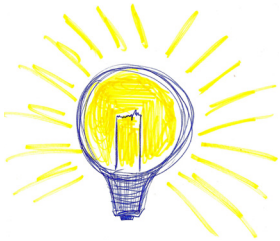


"With walking to school, I'll say 'Do you want your scooter or do you want your bike?' So going to school is a given, some things do happen, you have no choice about that, but you do have the choice of how. Or I might say 'Do you want to wear your shoes or do you want to wear your crocs?' you know, shoes have got to go on, but it's his choice."

Parent of KS1 child

5 Use humour

If you feel the tension rising, humour is a fantastic distraction. You could try making jokes, using physical humour (exaggerated facial expressions, or silly walks), being silly or feigning ignorance.

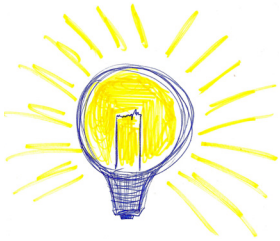


"I think it just takes the edge off the demand, I think. I'm trying to think of an example... Like getting dressed, I'll say 'Oh, let's take you to school in your pyjamas then!' and have a laugh about it, and 'I think your friends would quite like to see you like that, wouldn't they? They'd probably like to see what kind of pyjamas you wear', and just... 'Can you imagine what your friends would say if they saw you come in in your pyjamas?' And then she might start to laugh, and then slowly get dressed."

Parent of KS1 child

6 Use distraction

Distraction can be a handy way to temporarily press ‘pause’ and ease the child’s anxiety.

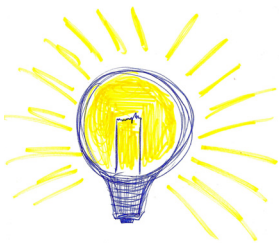


“She finds going to school quite stressful, so first thing in the morning the teaching assistant will say ‘Well that’s fine, why don’t you just come and do some jobs for me, you don’t have to go to class right now, just come and do some jobs, and you can give me a hand.’ And then she’ll get totally distracted, you bring her round, she’s got a string of things to tempt her with, then once she’s out of that frame of mind, she goes back to class fine.”

SENCO of KS1 child

Supporting children's social needs

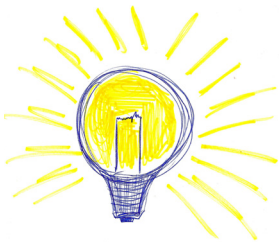
We sometimes need to help children with PDA to understand the social hierarchy and the subtle rules of social interactions by explicitly teaching them, as we do for children with other forms of autism:



"We've used social stories to help her understand that actually her peers aren't going to go along with all the things that she wants, and that she has to find a way round that, otherwise they won't choose to play with her."

SENCO of KS1 child

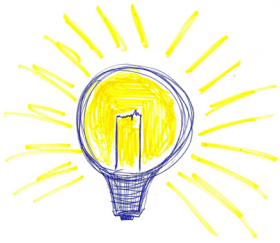
It helps to provide structure/scaffolding and careful supervision for interactions with peers, so that you can intervene quickly to offer support:



"I think that between the child and his peers, it needs to be engineered by an adult. Someone needs to intervene quite often with social interactions."

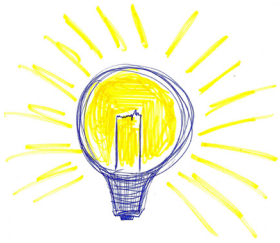
Teacher of KS2 child

Parents and teaching staff told us that sometimes it helps to meet the child halfway by 'throwing away the rulebook' about adults asserting authority and children obeying. They give the child some status within the school, perhaps by assigning a special role:



"The classic relationship of authority versus submissive, it just doesn't work. You always have to take a step back and not think like that anymore. I think that's partly what the teacher does... Obviously she's got to have rules and she's got to have more authority, but I think she's just very clever in the way she goes about it."

Parent of KS1 child



"They found that one way of getting him to sit still at 'show and tell' time every day is to get him to almost be a teacher and sit next to them and they'll say 'Oh, what do you think of this?' and he'll say 'That's very good work, well done'. He takes on that kind of role which enables him to participate in the group."

Parent of KS1 child

Anxiety busters

Creating trusting relationships and calm classrooms...

1. Be prepared

Have a range of choices available to the child, and think through how you will present them.

2. Be flexible

Be ready to scale back demands or change your approach if the child begins to panic.

3. Be indirect

Follow the indirect route from A to B, finding ways to 'ask without asking'.

4. Pick your battles

What's really important for the child, and for you? What should you hold firm, and what can you be flexible about?

5. Tune in to the anxiety and panic which underlies the child's behaviour

We don't chastise children who are having panic attacks, we support them to calm down.

Resources

All about me

This is a summary of the child's needs which parents and school staff can complete. It provides a quick and easy way of ensuring that all adults around the child understand how best to support them. It can be particularly useful when there are changes of staff or when supply staff come into contact with the child.

Feelings board

This can be used in the classroom to help children learn to identify and communicate how they are feeling, and then link this to what they need. A key way of reducing children's stress and anxiety, based on the good practice at Dawn House School, part of I CAN, the children's communication charity.

Suitcase of ideas

Linking with the ideas on page 8, this provides a visual way to summarise the approaches and strategies you plan to use for individual pupils.

Here are some examples of things you might need in your suitcase:

Visual timetable, to prepare for the day ahead.

Puppet or toy, to depersonalise demands.

Ear defenders, to relieve sensory discomfort.

Sand timer, to help child move to new activity independently.

Choice, i.e. present an activity in more than one way.

Feelings board or Emotions cards.

Quiet space or Exit strategy.

Reward. For example, ICT time, favourite book.

You may not need everything in your suitcase, but don't set off on an educational journey without it.

All about me

My name is .....

Here is a picture of me:

I have PDA, which means that I become very anxious when people ask or tell me to do things. To reduce my anxiety I will try to take control and may use lots of different strategies to avoid doing what you've asked.

I find ..... difficult

When this happens, I respond by .....

.....

.....

If I get cross it often means I am in a panic.
I need the adults around me to stay calm.

Confrontation never helps!

Here are some things you can do to help me:
e.g. give me choices so I feel more in control and less anxious.

.....

.....

.....

.....

Things I particularly enjoy and find interesting are:

.....

.....

‘Feelings board’

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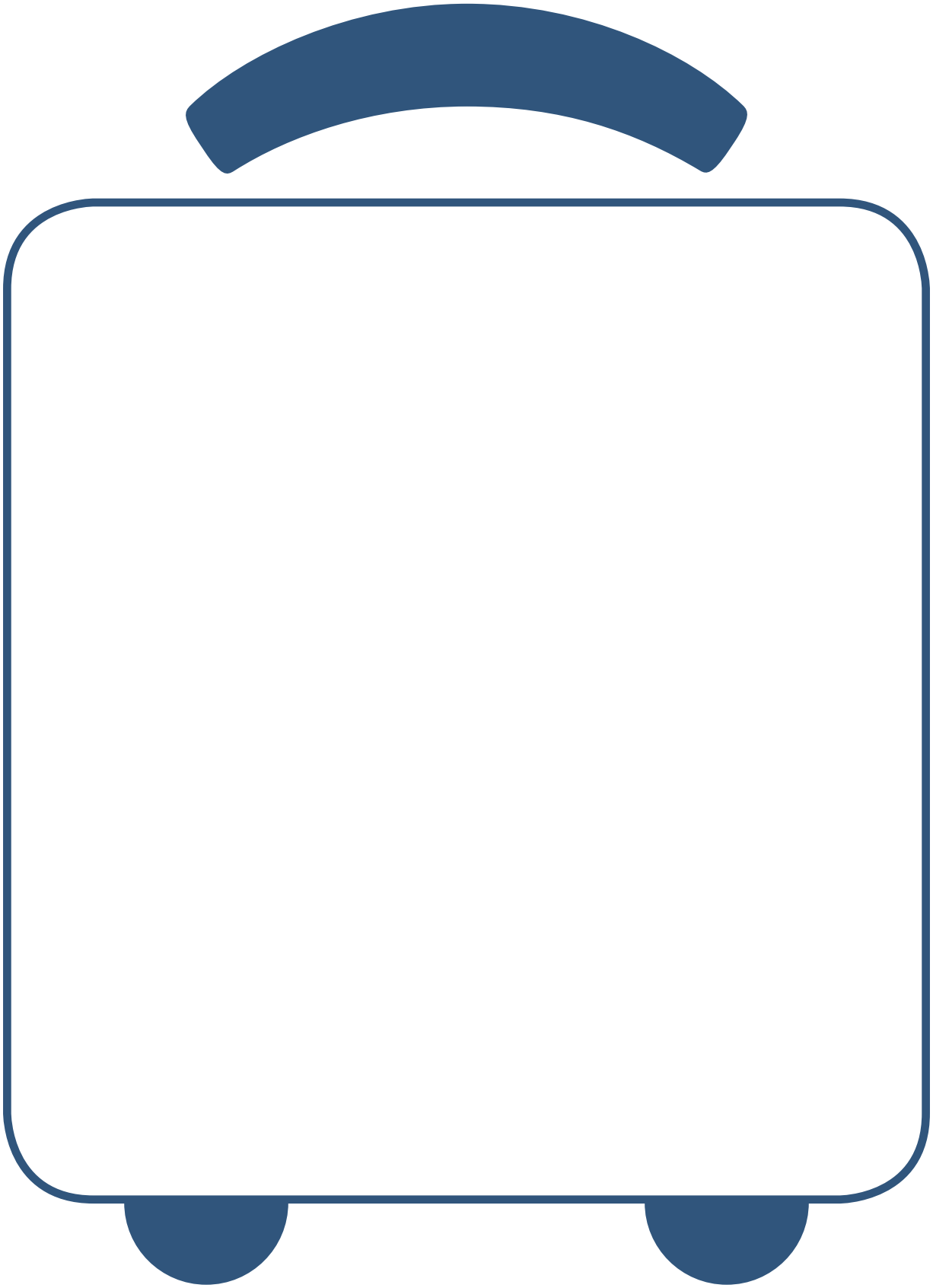
Approaches, strategies & resources



To find out more

Websites:

www.pdasociety.org.uk

www.thepdaresource.com

www.norsaca.org.uk/diagnosis-and-assessment

National Autistic Society ~ www.autism.org.uk

Christie, P., Duncan, M., Fidler, R., & Healy, Z. (2011). *Understanding pathological demand avoidance syndrome in children: A guide for parents, teachers and other professionals.* London: Jessica Kingsley.

Research papers:

There is a growing body of peer-reviewed research papers on PDA

Christie, P. (2007). The distinctive clinical and educational needs of children with pathological demand avoidance. *Good Practice in Autism, 8*(1), 3-11.

Gore Langton, E. & Frederickson, F. (2015). The educational experiences of children with Pathological Demand Avoidance. *Journal of Research in Special Educational Needs.*

Newson, E., le Maréchal, K., & David, C. (2003). Pathological demand avoidance syndrome: A necessary distinction within the pervasive developmental disorders. *Archives of Disease in Childhood, 88*(7), 595-600.

O'Nions, E., Christie, P., Gould, J., Viding, E., & Happé, F. (2014). Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q): Preliminary observations on a trait measure for Pathological Demand Avoidance. *Journal of Child Psychology & Psychiatry, 55*(7), 758-768.

O'Nions, E., Viding, E., Greven, C., Ronald, A., & Happé, F. (2014). Pathological demand avoidance (PDA): Exploring the behavioural profile. *Autism: International Journal of Research & Practice, 18*(5), 538-544.

Positive PDA

For more information about this booklet contact **positivepda@hotmail.com**

Booklet designed by Joe Windsor **joewindsor87@gmail.com**