

PDA

Pathological Demand Avoidance

Information promoting awareness and signposting to resources and further information

The National Autistic Society [NAS] now recognise PDA as part of the autism spectrum. Children and Young People [CYP] with a diagnosis of PDA share difficulties with those on the autism spectrum in social interaction, communication and imagination.

PDA is relatively uncommon, but it is important to recognise the behavior profile as it has implications for the best way to support the CYP. These pupils don't usually respond to the range of education strategies that support others on the autism spectrum.

What is PDA?

PDA was first described, in the 1980's by Elizabeth Newson, as a Pervasive Developmental Disorder. It is a lifelong disability.

The main difficulty for CYP with PDA, is their drive to avoid demands and expectations whether explicit or implicit. 'They have an anxiety-based need to control themselves, others around them and their environment.' [Daunt 2015]

The CYP appears to have better social communication and interaction skills than others on the autism spectrum, although they do still have difficulties in these areas due to their need to control the interaction. They can have good skills in social mimicry and role play and may become different characters or persons.

Defining Criteria for diagnosis of Pathological Demand Avoidance Syndrome

1. Passive early history in the first year.
2. Obsessive resistance of demands - resists and avoids ordinary demands of life...strategies of avoidance are essentially socially manipulative.
3. Surface sociability, but apparent lack of sense of social identity, pride or shame.
4. Lability of mood, impulsive, led by the need to control.
5. Comfortable in role play and pretending.
6. Language delay, seems the result of passivity: good degree of catch-up
7. Obsessive behavior.
8. Neurological involvement.

[Christie *et al* 2012]

Some characteristics of the CYP as a learner that you might observe in the classroom

- Refusing, giving excuses.
- Distracting or changing the topic of conversation.
- Bombarding with repetitive questions or noises.
- Negotiating or needing to have the last word.
- Complaining of physical impairment – my legs won't work
- Need to be in control.
- Explosive, panic driven physical outbursts or meltdowns.
- Threatening language.
- Very poor sense of self esteem.
- Wanting friendships but sabotaging them.
- Ambivalent about enjoyment and success.
- Very poor emotional regulation.
- Involvement in fantasy and role play.
- Impulsive.
- Obsessive behaviour – tends to be more social in nature, often directed at a particular person.

Other related characteristics:

Sensory sensitivities

The CYP will experience over or under sensitivity with some of their senses and will need help to support their sensory regulation.

Other conditions

PDA can be diagnosed along with other conditions e.g. ADHD, Dyslexia and dyspraxia. They may have been given other diagnoses prior to PDA .

Generalized learning difficulties can be present and their apparent verbal fluency can mask real difficulties in comprehension.

Supporting the CYP

Teaching Style

'A highly individualized style is needed, based partly on the understanding of demand avoidance but partly on the individual child's personality and tolerances. Staff need to understand the nature of the condition, and that demand avoidance is not something that the child can overcome by an act of will...

...Expect to be *indirect* in all demands made, rather than directive:

not – 'Now get on with your puzzle please' but 'I wonder what's the best way of doing this puzzle – I can't see how to do it...'

...Use lots of humour: coax, cajole, and even challenge if you do it humorously e.g. 'I bet you can't...'

...use *variety* in the pace of your presentation; variety in personal style; variety in learning environment.

...Disguise your expectations to the child... You need to limit your expectations, even if you know the child has better ability, remembering that - it's not so much that he can't or he won't, but more that he can't help won't ...

...Try to empower him by allowing more choice in activities, directions etc... offer a choice of two activities in which the one you really want him to do is the easier.'

[Prof Elizabeth Newson 2013]

Some school strategies used with CYP with PDA

- *The good schools guide: PDA*

- Allocate a key worker with whom the child can build a positive relationship.
- Provide choices e.g. 'this worksheet or that one?'
- Knowledge of the CYP, notice when demands need to be reduced but also when expectation can be increased
- Use a collaborative, respectful communication style. Allow the child a sense of control and be prepared to negotiate [start high and allow the CYP to feel that he has won]
- Visual timetables can help to depersonalise demands.
- Allow the child extra time to process what is said to them.
- Give the child responsibility for little jobs to help improve their self-esteem.
- Build the curriculum around their special interests.
- Create a safe space they can go to when needed.
- Be prepared to wipe the slate clean over and over again.

Top 5 tips for professionals supporting pupils with PDA

Ruth Fidler March 2016 Network Autism

1. **Collaborate** – with the child, offering approaches that recognise their strengths. Work with colleagues in school, the family and other agencies for a coordinated / consistent approach.
2. **Prioritise which issues to deal with** and collaborate with others to plan which strategies will be used to achieve them.
3. **Promote wellbeing** – demand avoidance is driven by raised anxiety, so reducing anxiety, promoting positive self esteem, self awareness and good social relationships is key.
4. **Use indirect approaches** which are creative, individualized and flexible and which can be adapted to synchronize anxiety and demand [days where anxiety is lower, greater demands can be tried, days with higher anxiety, demands need to be minimal]
5. **Allow additional processing time** – allow extra time to process incoming instructions, social and sensory information.

CT / TA: What sort of characteristics are helpful when supporting a pupil diagnosed with PDA?

[Webinar Phil Christie and Ruth Fidler 2018]

- Able to de-personalise difficult behavior.
- Able to wipe the slate clean as often as necessary.
- Reflective.
- Creative, informal, non-directive 'teaching' style.
- Not competitive – in fact a good loser!
- Calm in a crisis.
- Good listener.
- Team member.
- Confident enforcing boundaries when necessary.

References used:

Christie, Phil et Al. Understanding PDA in Children. 2012 JKP

Christie, Phil and Fidler, Ruth. Webinar – Educational provision and teaching approaches for children with PDA. 2018 NAS

Daunt, Julia. What is Pathological Demand Avoidance. July 2015 Network Autism

Fidler, Ruth. Top 5 tips for professionals support pupils with PDA
March 2016 Network Autism

Fidler, Ruth. Engaging children with PDA in learning & promoting their emotional wellbeing
2018 PDA society

May, Cathy and Whichello, Karen. Pathological Demand Avoidance
The Good Schools Guide.

NAS. PDA [Pathological Demand Avoidance Syndrome] information sheet.
2018

Newson, Prof Elizabeth. Education and Handling Guidelines for Children with Pathological Demand Avoidance Syndrome. 2013 PDA contact group

Recommended Resources For PDA

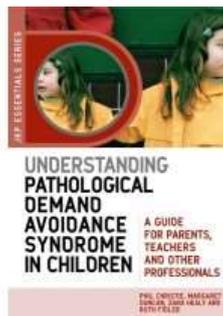


Pathological Demand Avoidance Syndrome - My Daughter is Not Naughty

Jane Alison Sherwin

Full of advice and support, this book is an account of one family's experiences of raising a child with Pathological Demand Avoidance Syndrome (PDA). It includes strategies to help manage PDA behaviours, information on obtaining diagnosis and raising awareness, and explanations to help readers gain a better understanding of the condition.

2015 £12.99 ISBN: 978-1-84905-614-4

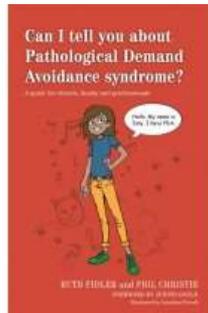


Understanding Pathological Demand Avoidance Syndrome in Children.

A guide for parents, teachers and other professionals. JKP Phil Christie, Margaret Duncan, Ruth Fidler and Zara Healy

ISBN: 8601200807752

This book gives an overview of Pathological Demand Avoidance Syndrome (PDA) and practical advice for supporting the difficulties it poses from diagnosis through to adulthood in different contexts e.g. school and home. The book also has a list of resources for further information and advice.

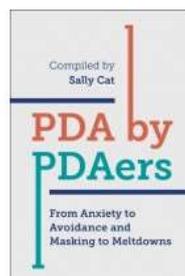


Can I tell you about Pathological Demand Avoidance syndrome?

A guide for friends, family and professionals. Ruth Fidler and Phil Christie, illustrated by Jonathon Powell

ISBN 13: 9781849055130 2015, Paperback £8.99

In this illustrated guide Issy invites readers to learn about PDA, a part of the autism spectrum, from her perspective, helping them to understand how it causes her to find simple, everyday demands very stressful. Issy tells readers (aged 7 upwards) about all the ways she can be helped and supported by those around her.

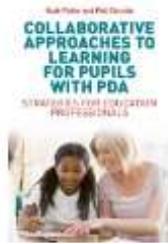


PDA by PDAers

From Anxiety to Avoidance and Masking to Meltdowns by Sally Cat

ISBN:9781785925368 2018, Paperback £14.99

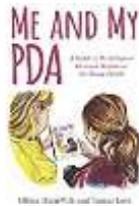
This book is a collection of insights and experiences from people living with PDA, adapted from their interactions on an online support group. It includes discussions of topics relevant to PDA, including work, relationships and managing meltdowns, it is recommended for both individuals and professionals.



Collaborative Approaches to Learning for Pupils with PDA

Strategies for Education Professionals by Ruth Fidler and Phil Christie
ISBN-13: 978-1785920172 £11.98

This book gives advice on implementing collaborative approaches to learning for supporting pupils with Pathological Demand Avoidance Syndrome (PDA) at school. Explaining why this approach is beneficial, it presents key information, advice and resources to help education professionals best support pupils with PDA, and also school staff.



Me and My PDA

A Guide to Pathological Demand Avoidance for Young People by Glòria Durà-Vilà and Tamar Levi

ISBN: 9781785924651 Nov 2018, £14.99

This picture book helps children understand their diagnosis, develop self awareness and implement personalised problem-solving strategies. A clear guide, complete with interactive exercises and colour illustrations.

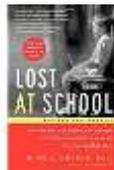


The Explosive Child:

An Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children. by Ross W Greene PhD

19 Jun 2014 £6.67 ISBN: 9780061906190

What's an explosive child? A child who responds to routine problems with extreme frustration. A child whose frequent, severe outbursts leave his or her parents feeling frustrated, scared, worried, and desperate for help. Dr. Ross Greene, a clinician and pioneer in the treatment of children with social, emotional, and behavioural challenges, knows that these children aren't attention-seeking, manipulative, or unmotivated. Rather, explosive children are lacking some skills flexibility/adaptability, frustration tolerance, and problem solving, and they require a different approach to parenting and schooling.

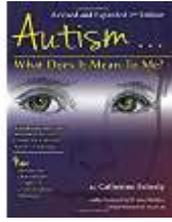


Lost at School: Why Our Kids with Behavioral Challenges are Falling through the Cracks and How We can help Them. by Ross W. Greene

£10.79 2014 ISBN: **0884750327699**

This updated edition contains enhanced methods for solving problems collaboratively, improving communication, and building relationships with children. Contents include:

- Tools to identify the problems and lagging skills causing challenging behaviour
- Explicit guidance on how to improve interactions with challenging CYP and reduce challenging episodes, along with many examples showing how it's done
- Practical guidance for successful planning and collaboration among educators, parents, and CYP



Autism...What Does It Mean To Me?: A Workbook Explaining Self Awareness and Life Lessons to the Child or Youth With High Functioning Autism or Asperger's
30 May 2014 by Catherine Faherty **ISBN-13:** 978-1935274919

Although it refers to HF autism and AS, book reviews have revealed that it can be useful for children diagnosed with PDA, in developing self-awareness.

Each chapter is divided in two parts: the first part - the *Workbook* - is for the child to complete, by writing or highlighting *What is True for Me* in lists of simple statements.

The second part - *For Parents and Teachers*- contains helpful tips/information for the adult who guides him through the exercises. The book will support the child making them more self-aware, means in relation to crucial areas of his/her life: friendships, fears, abilities, and much more..

Other chapters include:

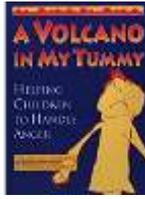
- Ways of Thinking Workbook
- The Sensory Experience Workbook
- Artistic Talent Workbook
- People Workbook
- Understanding Workbook
- Thoughts Workbook
- Happiness
- Communication Workbook
- School Workbook



The Red Beast: Controlling Anger in Children with Asperger's Syndrome
by K.I. Al-Ghani 2008 **ISBN: 978-1-84310-943-3**

This illustrated children's storybook is written for children aged 5+, and is an accessible, fun way to talk about anger, with useful tips about how to 'tame the red beast' and guidance for parents on how anger affects children with Asperger's Syndrome.

Reviews and professionals also recommend the book for children with PDA syndrome.



A Volcano in My Tummy: Helping Children to Handle Anger: A Resource Book for Parents, Caregivers and Teachers

16 Jul 1998 by Eliane Whitehouse and Warwick Pudney
(ISBN: 9780865713499)

Recognising the difference between anger the feeling, and violence the behaviour, this book, aimed at children between the ages 6 to thirteen, helps to create an awareness of anger. The book presents a clear approach to helping children and adults alike understand and deal constructively with their child's anger. Using easy to understand, skills for anger management, including how to teach communication of emotions.



Why Do I Have To?: A Book for Children Who Find Themselves Frustrated by Everyday Rules 2008 by **Laurie Leventhal-Belfer**
(ISBN: 9781843108917)

Why do I have to? looks at a set of everyday situations that provide challenges for children at home, with their friends, and at school. The author empathizes with children's wish to do things their way, explains clearly why their way does not work, and provides a list of practical suggestions for how to cope with these challenges and avoid feelings of frustration. Aimed for children who have difficulty coping with the expectations of daily living, as well as for their parents and the professionals who work with them.



What to Do When You Worry Too Much: A Kid's Guide to Overcoming Anxiety by Dawn Huebner (Author), Bonnie Matthews (Illustrator) 2005
ISBN-13: 978-1591473145

This is an interactive self-help book designed to guide 6-12 year olds and their parents through the cognitive-behavioural techniques most often used in the treatment of generalised anxiety. Easy to follow, this book supports children to work towards change.



When My Worries Get Too Big! A Relaxation Book for Children Who Live with Anxiety Paperback –2013 by Kari Dunn Buron
(**ISBN: 9781937473808**)

This easy to read, illustrated children’s book supports children to participate in developing their own self-calming strategies and introduces the 1-5 point scale.



Comic Strip Conversations: Illustrated interactions that teach conversation skills to students with autism and related disorders – by **Carol Gray**
ISBN-13: 978-1885477224;

Children can draw their own “comic strips” to show what they are thinking and feeling about events or people. Different colours can represent different states of mind.

Web resources to check out

PDA society www.pdasociety.org.uk

[Highly recommended](#)

Support for families and school. Resources for school and home can be downloaded from their website using the following links:-

[Education resources](#)

[Resources for Families](#)

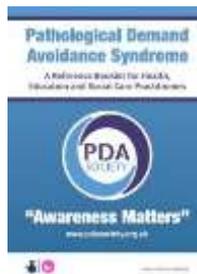
[Webinars and Videos](#) see below

[Books](#)

[Leaflets](#)

[Support and Advice](#)

[Reference Guide for Practitioners](#) free to download



Webinars and Videos

PDA Society Webinars

This series of on-line seminars explores aspects of the PDA profile and related issues.

[Understanding PDA - Part 1](#)

[Understanding PDA - Part 2](#)

[PDA & Mental Health](#)

[PDA & How Speech and Language Therapy can help](#)

[PDA & Family Resilience](#)

[PDA & Sensory Processing](#)

[Education Support & Strategies for Children with PDA](#)

**General - videos and webinars covering PDA and related issues.
Recommended for families, individuals with PDA and professionals
across all services**

[Channel 4 'Born Naughty?'](#) (children in episode one and four are diagnosed with ASD with profile of PDA)

[Radio 4 'All in the Mind'](#)

[Radio Interview with Dr Judy Eaton](#)

[Introduction to PDA by Laura Kerbey](#)

[We are Unique - Libby Hill](#) (speech and language therapist) talks to Kevin Healy about PDA

[Intro to PDA in children by Dr Judy Eaton](#)

[Strategies for managing PDA and mental health by Dr Judy Eaton](#)

Life with PDA - videos and webinars by individuals with PDA

[Pathologically Free-Spirited by Harry Thompson](#)

[My Experience of PDA by Isaac Russell](#)

[Radio Interview with Julia Daunt](#)

[Q&A with Julia Daunt](#)

[Pathological Demand Avoidance](#)

[Jellycat wild](#)

Families - videos and webinars by the parents of individuals with PDA

[Pathological Demand Avoidance by Neville Starnes](#) - series of 9 videos

[Bev HD](#) - a you tube vlog by the parent of a child with PDA

**Education - videos and webinars primarily aimed to education
professionals**

[The child with PDA as a learner by Dr Judy Eaton](#)

[Pathological Demand Avoidance by Neville Starnes](#) - education-related video

[Happy Learners Info](#) series of 4 information videos

[NAS / Axcis education webinar relating to educational approaches useful when supporting a child with PDA](#) – scroll down the list to find the PDA webinar link

[Horses Helping Children with Pathological Demand Avoidance](#)

[Do you wish you had a way to help others understand Pathological Demand Avoidance](#)- Blog by a special needs teacher which contains several posts about PDA

National Autistic Society website :

what is PDA? www.autism.org.uk

["Awareness Matters"](#)

[Online support forum](#)

[What is Pathological Demand Avoidance? An adult's perspective](#)

['Just do as your told!'](#)

[PDA and mental health](#)

[Educational and Handling Guidelines for Children with PDA](#)

[Educational strategies booklet](#)

[Peer reviewed PDA journal articles.](#)

Autism Education Trust [AET] www.autismeducationtrust.org.uk

Aims to improve education support for children on the autism spectrum

CEREBRA www.cerebra.org.uk

A charity set up to support children with brain-related conditions through research, education and supporting children and their families.

SIBS <https://www.sibs.org.uk>

Gives support for siblings of those with special needs and disabilities

PDA Awareness information compiled by Elizabeth Johnson, Specialist Teacher, Communication and Interaction.