



## ***Stronger Together***

### **2015 Parent and Carer Conference Survey Results**

Before the 2015 conference 138 parents filled in an online survey to help us identify common themes amongst their personal and family experiences.

Thank you to everybody who took part.

This document covers the open questions that parents answered on topics such as “what has been your biggest personal challenge?” to “what is the best advice you have received?”.

All quotes are verbatim from parents.

However names have been removed from every section apart from the question which asked “who would you like to thank”.

# 2015 Parent and Carer Conference Survey Results

## Contents

Page 1	“What has been your biggest personal challenge?”
Page 12	“What has been the best piece of advice you have received?”
Page 18	“What one piece of advice would you give to a parent/carer who suspects or has just found out their child has PDA?”
Page 25	“What has been your biggest reward in terms of being a parent/carer of a child with PDA?”
Page 32	“Is there anyone you would like us to say “thank you” to at the conference?”

## Question 1: What has been your biggest personal challenge?

- Juggling everything.
- **Getting him out of the house, to follow instructions and be self-motivated**
- Unable to identify the triggers. Unpredictable behaviour.
- **Feeling judged by others (and myself, at times) as a bad parent and my child being viewed as naughty.**
- Feeling like I'm not a good parent
- **Dealing with violent outbursts.**
- Giving up career, social life and the huge pressure on family, destroying marriage and limiting siblings' opportunities.
- **Watching the trauma child faces every day.**
- The physical violence when he was younger and how to manage that
- **Helping with his anxiety and dealing with his aggression.**
- Unbearable stress from repeated failure of placements.
- **Being heard! Never heard of PDA and we're still not 100% she's a 100% fit. We worry about her extremely low self-esteem, anxiety and obsessive behaviour.**
- Gaining support and diagnosis and dealing with the meltdowns
- **Being patient and forgiving**
- Being controlled
- **The fact that we are constantly exhausted and have to do battle with the authorities to even get noticed,**
- Never being supported.
- **Getting school to understand that it the way they deal with her and the social interactions that cause the increase in anxiety and then the challenging behaviour we have to deal with at home.**
- Learning to let go of control (of mine and my child's life) and handing the control to my child in a safe and guided way.
- **Learning to live a new kind of "normal"**

- Initially I went through phase of grief and lots of anger. It was hard to accept. And other people's reactions were awful ("at least it's not cancer"; I think my (very successful) husband has autism too). It felt very lonely. Still does.
- **Finding childcare is my biggest problem by far though- my son is very demanding and can be aggressive, so normal childminders won't take him. I haven't found a solution and it is unbelievably stressful.**
- Staying calm in the face of demand avoidance and challenging behaviour, and knowing you have to face it everyday
- **We knew something was not right. We asked for help/support from 2yrs. old. He was 13yrs. old when we finally got help!**
- With the family pushing & pushing. & going through a lot of difficult situations.
- **Family life not being as happy as I would have thought & balancing needs of PDA child and NT sibling & hearing that he wants to not be here**
- Feeling that I have let him down in some way, being misunderstood and judged
- **The biggest challenge has been dealing with meltdowns and what boundaries to put in place**
- Trying to get help with anxiety issues.
- **The disruption this has caused family life. Not being able to go out on planned activities because he refuses to get up.**
- This caused major stress for his father, who then walked out on the family because he felt that at this time of his life he deserved to do things he wanted. So I have been left to handle not only the general life issues of a PDA, but also the extra demands and emotional issues brought on by his father abandoning ship.
- **The biggest challenge I think is getting him to see how important education is and to get him any form of qualifications, then managing the frustration he has that he cannot just get to where he wants to be like 'Now'.**
- I could write a book about the challenges. Getting him out of bed and motivated to do anything- huge daily/hourly challenge that covers all aspects of his life. If there is no motivation in doing something then it just won't happen or it becomes a drag.

- When my son is around other children, observing that he is different.
- **Enabling my son in a system which does not accept the validity of PDA as a condition and in particular, the ability to make progress in an educational setting. Helping others (including professionals) to understand that he is not 'simply a naughty boy',**
- Balancing family life and trying to manage the education system and my son's best interests.
- **Managing the stress of constantly running into brick walls in terms of his behaviour and what to do about it - whilst trying to hold down a career and be a single parent**
- Gosh, the impact it has on our family life. For me it's living with someone who is so inconsistent, Jekyll & Hyde.
- **Dealing with my own fear & anger.**
- Lack of support with services and diagnosis, we had to pay for a private diagnosis
- **Self-belief - believing that I really do know my child best and my understanding of her behaviour as PDA driven is correct and I am not just a poor parent who doesn't discipline/set boundaries/follow routines correctly.**
- Unpredictable violent behaviour and self-harming.
- **Learning just to take each day as it comes as have 2 other kids never had to adjust things as much as we do know**
- Coping with unpredictable mood swings and aggression
- **Understanding and being able to communicate with her calmly**
- Challenging behaviour at home and spiralling mood swings. Getting her last primary school to understand the rising anxieties and to put appropriate strategies into to support her.
- **Being unable to read the signs before meltdown and not understanding his behaviour.**
- The exhaustion of having to find different strategies to get her to do the basic things.

- **The struggle of being seen/seeing myself as a "bad parent" and "not able to control" my son.**
- Constantly asking myself, what I have "done wrong" this time to cause a particular meltdown/angry outburst/aggressive behaviour
- **Daily life**
- Being believed that my child has a problem - it's not my parenting skills
- **Understanding his complex needs within a system which spent all its efforts blocking support and blaming parents for the difficulties**
- Getting the correct diagnosis
- **Battling with/dealing with outside agencies - LA, NHS.**
- Finding out what is wrong with my child when nobody will listen & trying to find ways around the demands.
- **Professionals being ill informed and malicious**
- Not taking the verbal and physical aggression personally! It feels like I'm under attack but have to try and remember that underneath there is a child with high anxiety levels.
- **No being able to predict or plan with any expectation of achieving the goal. Something as simple as buying a bra could result in a full meltdown**
- I am a grand-parent so I can answer observing the effect on the parents and family and not, until recently, knowing what the problem was and, now knowing, the lack of support.
- **Understanding my daughter, and how best to help her.**
- Working through an EHC plan and finding suitable education provision
- **Overcoming my own and my parents'/boyfriend's fixed ideas of discipline/parenting skills**
- Not being able to parent the way I'd like to, seeing my child struggle and feel helpless.
- **Getting his difficulties recognised by infant school staff and getting referrals to professionals.**

- Sudden outbursts, not worrying about what other people might be thinking during public meltdowns
- **KEEPING HER SAFE.COPING WITH MEETING HER NEEDS ALONGSIDE MEETING MY SON, WHO HAS ASD.**
- Having to give up work to care for her for the last 6 years
- **Effect PDA has on our family. Trying to make grandparents understand.**
- Don't know how to manage it
- **Helping them to make friends**
- Dealing with my child's depression is the worst.
- **Being believed by professionals**
- No one understands or sees what I see. Isolation in dealing with this constantly.
- **Having to relate to my son in a manipulative rather than straight way, and constantly think about how he will respond.**
- Making people understand that PDA exists (including the local CAMHS) and that he had it. It wasn't officially recognised. He still doesn't have an official diagnosis
- **Nobody understanding just how difficult everyday life is.**
- Dealing with the battle of parents in his previous school. They did petitions in front of us in the playground to demand their child doesn't mix or work with my son. They made countless complaints and alienated him and myself.
- **Not being able to plan things as a family.**
- Feeling as no one believes you.
- **Trying to get a diagnosis; the lack of support or care that matches her complex needs**
- Coping with physical aggression.
- **Lack of recognition, had to fight to be believed, fight for support, fight for help at school**
- 24 hour challenge of behaviour and we are currently housebound
- **Being taken seriously in a borough that doesn't recognise it.**

- My mental wellbeing and capacity to cope, keeping our family together, raising awareness on PDA with school staff and maintaining good communication with teachers
- **Getting the right support for her**
- Fighting to get heard by professionals and getting support.
- **Managing my son's violent meltdowns, being isolated and not being able to leave the home to do everyday tasks.**
- Getting others to understand, listen; she could have been helped earlier instead behaviour issues got her taken away, assaulted, in a minibus crash and hospitalised twice under others care then sent back with no help and traumatised
- **Retaining own sanity and staying married**
- Managing unpredictable behaviour at home (aggressive - verbally and physically) towards parents and sibling
- **Coping alone**
- The general demands; dealing with Meltdowns (especially in public), Having him take control and not me! The list goes on....
- **First, understanding why he has such problems, and second, trying to find a solution.**
- Dealing with the powerless is the problem - it's heart-breaking to watch your child 'disintegrate'
- **Understanding why my son does what he does - Try to understand how he feels**
- Education or lack of
- **When he stopped going to school and stayed in bed all the time. Eventually CAMHS had him sectioned and he went to an adolescent psychiatric unit for a month, to get a diagnosis (autism? Asperger's?). We never got the diagnosis because he got ulcerative colitis. This didn't respond to any treatment, so he had to have a total colectomy operation. He now has a colostomy bag - which he will obviously have for the rest of his life.**
- Lack of understanding and appropriate support from those paid to provide support
- **Having no support network and his constant strange behaviour towards me.**

- School attendance
- **Achieving a diagnosis and constantly fighting for recognition and understanding of PDA.**
- Severe off the wall behaviour coupled with school refusal starting suddenly. Treated as parenting issue and written off as weak ineffective parents who were over anxious. No assessments until grandparents finally realized severity of the issue and kindly funded them.
- **Socially isolated. The 'support' provided by school being completely inappropriate for my son. Parenting support also a complete insult. Felt like they had a GCSE in child behaviour and we had PhD level in comparison. If we said didn't think it would work we were told we were too weak and ineffective and felt bullied.**
- Other people and their lack of empathy and understanding.
- **Relentless. Exhausting. No support. Terminated my career for now and probably permanently impacted my earning potential**
- Impact on my marriage.
- **Not knowing about PDA, my son has had a diagnosis for 4 years but there was always something that didn't add up and once I was informed about PDA it made sense**
- Being an advocate for my son, always having to stick up for him when people don't understand.
- **Non-compliance and anger**
- Fighting for an education for my son
- **Managing meltdowns**
- Too difficult to answer
- **The early years were really tough, when he was very aggressive at school and less so at home.**
- Trying to help my son with strategies so he was less aggressive.
- **Feeling that I should be doing something about the "inappropriate" behaviour that happens but knowing that if I do, things will escalate into a meltdown.**

- Lack of understanding and intolerance by others.
- **Coming to terms that your life with your child is not going to be how you imagined it, that you are not going to be able to go traveling to far off places and show him the wonder of the world, that you are not even going to be able to go to museums, or festivals. That your life is now based around your house as your child needs to stay home.**
- Dealing with the anger and refusal
- **Social services and being placed on a section 47 for neglect and the focus being on our parenting and attachment to son, when we are parents to 3 and have an older child with ASD. The mental stress and impact on our relationship as parents has been immense. Ironically the only progress in helping our son has been via our persistence and NOT via Social Services. After a year on a CPO s47 our new social worker actually said today "why aren't you being supported by the disabilities team?" system is NOT working. We deal daily with verbal and physical assaults from our child. Our house is damaged; we've physical and mental scars as have our other children. We love our son and we won't stop fighting to get him the help and support him and we need. We are our child's best advocate.**
- Not having a never-ending supply of patience!
- **Been believed. Going through child protection investigation with allegation of induced and fabricated illness (all found to be totally unfounded) but most of all dealing with anxiety relating to school, their ignorance, the fact that they are allowed to do this and my son (amongst many others I know) suffer what can only be described as emotional abuse due to education and the current system**
- Getting a diagnosis and for people to see that it is not a parenting issue
- **Patience and a change of personal views on how i believed children should be brought up**
- Dealing with challenging behaviour. Fighting professionals. Lack of support. Isolation.
- Getting listened to as my son holds anxieties at school and out. If they don't see it then it doesn't exist right??

- Living with her constant violent meltdowns constant anxieties about nearly everything she doesn't draw breath for five minutes the effect it has on the other two children I could go on and on she was out of s hook for 15 months treated like dirt had massive negative impact
- Isolation - child needs so much control, I can't leave the home.
- Their anxiety and temper tantrums, CAMHS refusal to recognise PDA, inappropriate school setting and lack of understanding of girl's needs.

## Question 2: What has been the best piece of advice you have received?

- Listen
- **Use challenges and missions**
- Unbroken record, repeating instruction with the same calm tone of voice.
- **When capacity is low, reduce demands. When capacity is high use this opportunity to teach/give increased demands (the dials analogy).**
- Pick your fights and don't make everything a battle ground
- **Currently being assessed, no advice yet received.**
- Trust your understanding of your child; protect them from the ignorance and misunderstanding of most professionals.
- **Thinking of meltdowns as panic attacks and being therefore able to give reassurance and understanding**
- You know your child best.
- **Never give up on her.**
- It's not anyone's fault. Use distraction and humour to help diffuse situations.
- **To not give up and to not take it personally**
- Keep looking forward. Speak out positive experience regularly and give little time to remembering the negative
- **Understand your child**
- Probably the most helpful bit of advice was to read up on PDA in the first place. Without that lightbulb moment, I dread to think where my family would be now
- **Learning how to lower demands at home, change language used and supporting the need to control and lower anxiety levels.**
- To see a meltdown as a panic attack, something however unpleasant, damaging and destructive that my child has no control over.
- **Be kind to yourself.**
- Start each new day afresh

- Website support from PDA Society & Research & parent support group.
- **Trust your instincts**
- You know your child best
- **When child is anxious - use less words**
- Pick your battles.
- **"To preserve, little steps. You might not think you are achieving anything but have little targets and keep working on those.**
- "Choose your battles- you cannot win them all, so be selectively productive."
- **That he can't help how he reacts when he's anxious.**
- To stop looking at the typical ASD diagnosis and strategies and to consider the possibility of PDA.
- **Accept that each day will bring different challenges for us and for my son and his reactions will differ depending on his anxiety levels.**
- "Keep doing what you are doing, you are doing a good job" (said by CAHMS at assessment last year)
- **Ignore a meltdown; don't engage with the roller coaster he's on. It will soon pass.**
- Pay for a private diagnosis
- **Remember that your child is always doing the best they can in any situation given the skills available to them - change the situation to meet the ability at the time of the child.**
- Avoiding direct demands.
- **"Do what you think is best you know your child better than anyone."**
- None
- **To diffuse a situation e.g. walking away**
- Understanding about the challenges of ASD and PDA and how to support and deescalate challenging behaviour.
- **Pick your battles. Decide what your goal is and concentrate only on reaching that goal.**
- Understanding that the behaviour is anxiety driven.

- Seeing meltdowns as panic attacks.
- **She is your child; you know her best**
- To trust my instincts and keep pushing for assessment
- **Many years ago a private SALT said to me, 'Stop telling him what to do.' I went home and put a glass of water in front of him and said 'there's a drink if you would like it'. He drank it immediately! It was such a lightbulb moment which changed my parenting forever.**
- Stay non-confrontational when dealing with their meltdowns -
- **Trust your gut. Question everyone else's advice and/or motives.**
- Try and stay calm' it's not their fault, they can't help it.
- **To look at what you could have done to prevent the issue**
- Start each day afresh - don't carry over any resentment or bad feeling from the previous day.
- **Try to stay calm**
- I am not a parent but wanted to take part in the survey - I am a professional
- **To choose your battles.**
- It's 'can't' not 'won't' which governs behaviour
- **PDA society - back off with the demand when a meltdown occurs**
- Do what works for you not to focus on other people's prejudgements.
- **The correct way to handle melt downs. We used to waste many hours trying to get control of our son and it was very stressful for everyone in the family.**
- Be flexible, pick your battles
- **To let things go, making her more anxious and unhappy to fit 'into a box' just isn't worth it**
- Choose your battles
- **They can't help won't!! ...don't expect anything back in return**
- Finding the PDA website and realising that it was rules that were the problem
- **Stay calm**
- To stay calm, confident and always be there for her no matter what!

- Trust your instincts, Never give up, fight for justice
- **De-escalation and non-violence**
- Cannot think of any
- **No-one has ever given me any advice - I worked it out for myself, most 'experts' have been useless.**
- Temper tantrums are anxiety attacks.
- **Learn as much as you can and deal with what you know without worrying what others think of you or your child. My counsellor once told me "you know what your battles are; others don't know what problems their child will bring as they get older so you're one massive step ahead".**
- To let your child have time and stay calm.
- **Stick to your instincts as a parent, you know your child best**
- Find another way of asking / telling him what he needs to do.
- **The PDA society and the pdaresource.com is the biggest help. Best advice was ... Reduce and rephrase demands**
- Jane Sherwin's book!
- "djfkjfhjglakgjhllmm,jjkkjfggh ytrryyh 76trt tyv5t5j;f#. These are my boy's thoughts!! Off the top of my own head I would say ""pick your battles"
- Choose your battles!
- **Never stop fighting for her rights**
- Not to argue back with my son and that it's the anxiety driving him and remembering he is not in control when in a very 'controlling meltdown'
- **At the last conference having a lady with PDA speak concreted the demands put on by life but also herself**
- The power of non-action and the importance of knowing when to step back and pick a battle.
- **To have no expectations (re: child's behaviour and plans for day) - enjoy positive moments when they occur.**
- You know your child best

- They are not doing because they want to but they have no choice (i.e. not doing it on purpose)
- **Anxiety is at the root of it all.... But never had advice that's helped with that**
- Not sure we have yet!!
- **Believe in yourself**
- Develop psychological strength. This also applies to dealing with neuro-typical children!
- **Don't take behaviour personally, as it is driven by anxiety and a need to feel in control**
- No real advice, but being told that I am a good parent.
- **Don't push!**
- To stay calm when my child melts down.
- **View difficult behaviour as anxiety and look to decrease anxiety rather than directly challenge behaviour as it happens.**
- Positive parenting techniques have transformed our lives. We do not use punishments nor rewards at all. This has removed all pressure from his life and he is now better able to cope with demands.
- **Probably Paula Webb's kind supportive words (PDA Society) telling me to go with my gut instinct and pursue a specialist placement for my son.**
- I haven't really been given much advice unfortunately
- **That it is not his fault and he doesn't mean it.**
- Try to Remain calm in the face of their anger and think out of the box to understand what may be troubling them
- **Do not take it personally**
- "Reduce demands to a minimum when tolerance is low"; and "Learn as much as you can about the condition and see the world through his eyes"
- **None**

- Start each day afresh, balance tolerance and demands and ignore the sceptical people who say PDA doesn't exist (oh and speak to other parents - in person or online - to get support).
- **Not to react to pre-meltdown behaviour, also not to react to an emotion with logic, but to respond with an emotional response (not a negative one, but an empathetic one).**
- Remember that your daughter is still the same sweet, loving little girl she was before the diagnosis. When times are hard, try to remember that.
- **To autonomously parent and give control to my child.**
- Joining a parent carer group
- **You're not alone. You're not bad parents. Stay strong, network, learn, and share.**
- Try using humour to diffuse a tricky situation.
- **Go with your instinct - you know you're child best, listen to him, believe in him and advocate for him**
- That as a parent you know the child best and don't give up fighting for help.
- **Do whatever works for YOUR family**
- Keep fighting for diagnosis. Ask for a second, third opinion. Don't give up.
- **Take every hour as it comes**
- Different strategies needed
- **Dial back the demands.**
- None yet
- **"It is a Life Long Disorder"**
- "Good Education will be the key to his success."

## Question 3: What one piece of advice would you give to a parent/carer who suspects or has just found out their child has PDA?

- Keep on pushing for support and shout loud!
- **Use distraction and challenges,**
- Keep telling and showing your child that you love them.
- **Don't sweat the small stuff**
- Seek out other parents and support groups. Read up you need to be the expert.
- **Things do get better**
- Join the PDA Society and other support groups, e.g. on Facebook. Find links with other people who live it and understand or you can feel isolated.
- **Be prepared for much misunderstanding from other parents and professionals but you understand your child best and will need to be strong in fighting to gain the best provision for their needs.**
- Keep pushing for help!
- **Be prepared to fight for help and support**
- Get connected with other parents. They are the experts!
- **Look to get a formal diagnosis, it opens doors for support, help and a better understanding of your child**
- Forget everything you ever knew about parenting and start from scratch. Remember that nobody has spent as much time with your child as you have. You are the expert on your own child's needs.
- **You know your child best, learn to understand that the behaviour is your child's way of trying to communicate they are have a problem.**
- Trust your instincts, as a parent you know your child best.
- **Give yourself time-this is a huge thing to deal with and it will take time to understand, accept and get better at dealing with it. Don't expect others to "get it"- and although that feels awful, if you don't expect others to understand, it will be less frustrating!**

- Pick your battles. Try the PDA strategies and see if they work - if nothing else it adds to the evidence of PDA and may help others adapt and understand.
- **Read as much as you can. Try to stay calm. Observe situations & keep a diary as evidence to support your child's assessment. Show this to GP and others.**
- Research & trust your instincts
- **Your child is unique with unique strengths and abilities**
- Fight for the right support both at home and school, as traditional ASD methods are not effective
- **Try to understand your child and see things from their point of view.**
- PDA is a label like all of the other syndromes, but get a diagnosis as it will help you to understand how to help your child achieve and succeed. It is not an excuse for not achieving.
- **Find out all you can about the condition**
- Read and act upon the strategies and advice outlined in the book, Understanding Pathological Demand Avoidance Syndrome in Children: A Guide for Parents, Teachers and Other Professionals...
- **Don't expect the typical strategies that help autistic people to be effective for their child**
- Push for a diagnosis or an acceptance that your child has this - once this happened things started quickly changing at CAHMS and school
- **Don't give up.**
- Get support, learn about your child's condition accept that you have to change your behaviour as you're unlikely to change theirs.
- **Read, read and read some more.**
- Join a family PDA support group.
- **Read as much info on the Internet as you can join the support groups as they are a lifeline they are the ones that truly get how your feeling and fight for help from the start.**
- Learn how to manage demands on the child to minimise onset of anxiety

- **Try not to take things personally**
- Go to the GP and discuss the behaviours and as a parent trust your instincts. Don't let professional intimidate you.
- **Start each day as a fresh start. With love, support and guidance you and your child can get through anything.**
- Join a Facebook group! It is reassuring to know you are not alone and you have an instant group of friends who can give you help, advice and support.
- **Trust your instincts and keep talking to people (doctors, friends, anyone) to find out more and get to the truth.**
- Seek out as much support as you can
- **Get in touch with the PDA society and join the PDA support groups**
- Never give up and try to raise awareness with professionals
- **Stop telling them what to do.**
- Let them take control and make their own decisions if they are reasonable and allow them to negotiate and feel they have won."
- **Remain calm when dealing with them your anxiety will increase theirs significantly. Treat as an equal (mini adult)**
- Trust your gut. Question everyone else's advice and/or motives. NO-ONE else will ever advocate for your child like you will.
- **It's a hard struggle to anyone to listen but keep going.**
- Read and let them lead
- **Read the PDA society website - excellent content.**
- Don't let anyone discourage you in your pursuit of a diagnosis and you're not a bad parent.
- **Use scaling to try to identify how anxiety is triggered, then escalates and think of ways to reduce anxiety to return to low arousal**
- Look at the advice and suggestions on the web and learn as much as possible about the condition.
- **Use PDA society; find other parents to talk to, online or face to face.**

- Look at the advice given by the PDA society and the YouTube videos provided by bluemillicent
- **They aren't alone. It's not their parenting techniques to blame.**
- Get to know your child and record the things and you notice think and suspect around incidents and behaviour. It's been very helpful in being able to educate the people that work with him as well as for me thinking up strategies to help at home.
- **Try to build up a supportive network**
- Find out as much as you can, when you can and feel strong enough to take it all in.
- **Join a forum or support group so you know you're not alone, and get information to share with family, friends and schools.**
- Read as much as you can about PDA & join Facebook groups etc. Push for diagnosis if you suspect & don't leave too late.
- **Talk to other parents**
- To stay calm, confident and always be there for her no matter what!
- **Help to spread awareness - fight for more widespread assessment and diagnosis.**
- Forgive yourself no matter what they say- you are NOT to blame - it is not ' bad parenting'
- **Cannot answer this - we have just discovered PDA ourselves**
- You are the expert on your child - keep notes of everyone and meetings with every so-called expert you see because the experts will let you down.
- **Try the techniques, things will get better. It is not your fault. You are not a bad parent.**
- Talk to others in the same boat but try to stick with positive people that have been through it and come out the other side. It's not helpful to sit there hearing people just moaning about the negatives of the situation, you need to know you can come through it.
- **To get in touch with PDA society. Let them know they are not a failure as a parent.**

- Love your child unconditionally, they are not doing it on purpose ...behaviour is usually due to anxiety, be calm, look after yourself ..don't forget your needs
- **Do not take anything they say or do personally or to heart.**
- Use the strategies , read and learn as much as you can
- **Educate yourself on strategies that work. Don't listen to professionals who know about ASD they don't have all the answers!**
- Join the Facebook forums; a wealth of support and advice.
- **Always try to remember to look after yourself**
- Tell everyone and share the techniques they should be using with your child
- **Learn to recognise the anxiety in their child that it's not bad behaviour and to learn to back away to reduce the anxiety, read as much as they can about PDA and to use the strategies.**
- Believe in yourself; put yourself in your child's position - enjoy your very special child
- **Rethink how you approach your child with regard to discipline.**
- Make use of the PDA website and forum - so useful to hear other parents in similar position to yourself and that you and your child are not alone.
- **Stick to your guns and listen with your gut reaction.**
- Now try and move forward armed!
- **It will take time, but observe and understand it and be direct when explaining to those there to help**
- Don't give up
- **Believe in yourself you are the expert on your child**
- You are the one that's going to have to change, because they can't.
- **Don't take no as an answer - fight the system.**
- Forget what you know about ASDs
- **Get as much support from family, friends and other PDA parents as possible.**
- Learn as much as you can. PDA society forum, Facebook groups, the books and blogs have been a lifeline

- Focus on what works for you and your family and ignore advice from anyone who doesn't understand PDA.
- **Read lots and believe your instincts despite what other professionals tell you.**
- Don't take the defiance personally
- **Find some support. Other people who understand the challenges**
- Read up as much as you can. Change the way you parent your child using PDA guide lines and **CHOOSE YOUR BATTLES** grow a thicker skin don't let others opinions or comments upset you
- **"\*Do your homework: read as much as you can about the condition, observe your child and learn about their 'triggers'. Put strategies in place to reduce this behaviour"**
- **I wouldn't choose to give someone else advice**
- Read lots of books and information (and watch the videos) and try a different approach with your child as it can make a difference. Also have a look at Dr Ross Greene's (author of the explosive child) approach.
- **Not sure, we're only just finding out and getting our child diagnosed...**
- Don't panic!
- **To step away, breathe and then realize their child has not changed. PDA is just a different way of being, and takes a different kind of parenting.**
- Get some sort of plan in place to deal with them using PDA guidelines and get school and other professionals on your side
- **Educate yourself. Network, share you know your child better than anyone else. Be your child's advocate, their voice. Remember definition of HATE is has anger to express. In their anxiety as a parent you feel what you think is hate. It isn't your child doesn't not have the coping mechanism to cope with demands and pressure and change. Be the parent don't get drawn into the child like rages be their calm. Be the safe the reassurance when they need you to be. Advocate their achievements no matter how small. Most of all stop being afraid, you're NOT alone.**
- Look at the PDA Society website for lots of useful information.

- You are your child's advocate. If you can afford private support (e.g. diagnosis which then supports recommendations for EHC process - go for it. Go through appropriate channels and don't force your child into situations that they can't cope with. Listen to them and believe in them
- **As above and that the children can be very rewarding**
- Find parents in a similar position on Facebook or with a support group, the best advice comes from those in the same situation
- **Join the PDA groups on Facebook.**
- Relax as much as you can. Never stop fighting for ur child
- **Never give up fight all you can make the professionals listen grab the good days and remember them when the bad days happen**
- Go to the GP and ask for an ENC referral. I'd offer to go with them to GP.
- **They cannot help their tantrums, it is a cry for help and they need love and support to get through it. They don't want to be like this and they don't want to hurt their parents. They need our understanding.**
- Find out as much as you can about the condition your child has by reading, attending Workshops, Conferences but most of all seek the help and advice from other Parents living with a child who has PDA. Then you will be able to be equipped to Parent your PDA child to the best of your ability.

## Question 4: What has been your biggest reward in terms of being a parent/carer of a child with PDA?

- I look at life differently and simply!
- **Yet to find one**
- When my child is happy and making an effort to control his emotions.
- **Seeing her develop at her own pace.**
- There is never a dull moment.
- **When he laughs**
- Using strategies that work and seeing him develop into a fine young man
- **Making me become a more open-minded, understanding and tolerant person and the sheer pride I feel when he achieves something despite the challenge he faces.**
- Well, we just wouldn't be without her. She has a heart of gold and a fantastic imagination :)
- **My child can be the most thoughtful and loving child of all during a good day**
- Living life with a 'fun' factor
- **The charm and unique personality makes me smile**
- Most of the time, she is a real joy to look after. She has a wonderful character and a bouncy, toddler's enthusiasm for things that make her happy - it is infectious.
- **Having the most amazing fun loving yet challenging child and enjoying the happy times. It's rewarding seeing them achieving when they don't believe in themselves.**
- The privilege of exploring the world through my amazing daughter's eyes.
- **"I don't know yet. I can't see any good sides. Life feels pretty rubbish to be honest!**
- It isn't what this survey is looking for but getting special LEGOLAND tickets (i.e. jumping every queue) was fabulous!!
- **Seriously though, I am very depressed about it all, and I can't see a "reward" at the moment. "**
- Enjoying the times where it all works
- **Every day is precious. Seeing him happy, relaxed & in control is exciting.**

- When my child says that I'm the only one who understands him
- **Seeing him develop and enjoy things that have been a challenge**
- A sense of pride/love as he learns new things and continues to work hard at the things he finds difficult
- **Watching her settle into secondary school so well after appropriate support was put in place.**
- The fact that my son will come to me and ask for help and we will work things out together. He has come a long way and we have a way to go still.
- **His wonderful sense of humour**
- Seeing his growth and development and enjoying his individuality and fun.
- **Any occasion when we help our son overcome and challenge and as a result he has a really positive experience.**
- There is a reward?
- **His affection**
- Moments of progress and insight, however fleeting
- **Seeing my daughter grow and develop when allowed to do so at her own pace.**
- Being able to share advice and experiences with other parents
- **Sorry but at the moment can't say as times have been hard for a while.**
- The rare times when he is calm and caring
- **None as far as we can tell**
- They can be the most challenging but also the most loving and fun children. To see my daughter achieve what to her was her biggest fear and have supported her and helped her is very rewarding.
- **Seeing him smile. His happiness is everything.**
- She is an amazing child. I love to see how she finds her own strategies to help her get through life.

- When he trusts me and is gentle/loving, the way he is increasingly able to understand and talk about his issues and not just feel angry and negative about them/himself. To see him grow in self-confidence.
- **Raising awareness for other families that are in the same predicament that we have been in as in not being listened to by professionals**
- Growing stronger and finding support from other parents. Finding a condition that fits my child after much soul searching and personal turmoil. Seeing my beautiful son's potential and realising how unfairly he has been treated by ignorant professionals.
- **To see his opposition now reduced to a point where he is calm, happy and willing to comply with instructions - unless someone is overly directive or if he is being backed into a corner. Mainstream school would never have been an option.**
- Finally getting the handling strategies correct and seeing him progress to mainstream college and succeed in education for the first time in his entire educational career.
- **There are so many rewards. Boy makes small steps or giant leaps forward every day. Seeing his self-esteem and confidence increase incrementally all the time is probably the most rewarding thing of all. Seeing him happy in his own skin is the best feeling ever.**
- Being a mum of a wonderful child
- **He is a beautiful child**
- Hearing 'I love you' or getting a cuddle!
- **I have great tolerance.(not diagnosed)**
- We have set up a charity in the USA.
- **Treasuring those times however brief when she feels happy.**
- Learning more about myself - learning what I believe in as a parent, learning that I have PDA as well, (which has increased my confidence 100 fold!) learning how strong and flexible and loving I can be!
- **Seeing her cope with things she that she's previously struggled with.**

- Building his self-esteem by finding friends for him. I started a Lego club for kids with social difficulties in my son's year and I taught them how to play fairly co-operatively. One of these kids became his best friend at school even though they are in different classes. School reported that the friendship has been a very calming and positive thing for both boys. No more melt downs at school.
- **The small goals being reached**
- Despite the challenges, my daughter can be very loving and those moments keep me going.
- **Understanding her unique personality by learning about how she functions and struggles with the world. It has made us much closer.**
- Things are very bad for our family at the moment with the lack of support from family members, we would not call it a reward more relief when diagnosed as we had been blaming ourselves for his behaviour in bad parenting
- **Not sure**
- Great personality
- **My daughter has not said she loves me for a long time but I know she does in the occasional little things that she does for me and with me - and knowing she's going to be alright**
- Confidence and positivity in knowing we knew better than the 'Professionals' and we were right all along
- **He is a remarkable and extremely talented individual**
- So many of the adults she has interacted with find her enchanting and enthusiastic. She charms them into doing things for her - what a skill to have!
- **To have much more understanding of individuals and families dealing with ASD issues, hidden disabilities. Also to know I'm raising my wonderful son in the best way he can be raised.**
- Being able to help others in similar situations as you end up learning that there is not a great deal of help out there.
- **I view life in a different way , meeting other parents with similar children**

- We are very proud of our son our biggest reward is when he smiles and laughs which is not very often but when he dose he is a dream.
- **She's so clever , seeing her thrive when we adjust our parenting ... Amazing**
- Having a lovely little boy during our positive times
- **The same as any parent I would imagine; finding something he enjoys, the days when he will leave the house and enjoy being a kid.**
- I cannot see anything at the moment
- **I learn something new about her nearly every day. She is so loving**
- "Fighting hard and getting all the support in school he needs.
- **Understanding his condition and seeing him getting back into education (still only part time) and seeing him become more confident knowing that he is being understood. "**
- The joy and love she can give, even though there's really hard times there always there
- **Learning coping strategies and one to one he is lovely. Has provided me with lots of material for my artwork!!**
- Struggling to find one.
- **Knowing he is more special, now a very loving little boy (when he wants to be)**
- Our strong bond - it is frightening, but we are on the journey together.
- **Knowing just how special our son is - he has a lot of strengths and can see things from a perspective that is genuinely interesting**
- Seeing how far we have come, when everyone said put her in a home and forget her. Glad I didn't take that advice
- **Knowing I am trying everything i can to learn about ASD and PDA and at least partly meeting my child's needs**
- Seeing him playing normally with other kids.
- **I'm still waiting!**
- The close bond we have developed in facing the world together.
- **Seeing the anxiety decrease and seeing the lovely side of our son appear again.**

- It is always challenging and I love that I have to learn constantly!
- **Being more compassionate about peoples' short comings and fallibilities. I'm probably more forgiving.**
- The love my son gives me - he's very sensitive and loving
- **Having a highly intelligent, bright and funny individual**
- She has qualities that totally set her apart from other children
- **Seeing my son come through some very difficult times and overcoming some anxiety's and most of all seeing past the PDA behaviour to the loving kind helpful bright funny boy he is**
- I have found out 'who my child REALLY is' and 'what makes him tick': he is a child with an awesome sense of humour and a highly developed imagination. He is an brave, determined and an overcomer. He is affectionate and charming -though he doesn't know it and he has a future. I adore him.
- **Too difficult to answer**
- Seeing my son start to be able to regulate his emotions better, and find his own strategies to stop him having meltdowns and to see him help others like my younger son who are struggling like he used to with emotional regulation. Also to see him finish school with GCSE's and move onto a college course in a subject which he is interested in (Science)
- **The trust he puts in me because he knows I'm trying to make things easier for him (when he's not in high emotional state)**
- To see him starting to understand why he gets angry and frustrated, to see him starting to find coping strategies, listening as he tries to explain PDA to others which helps him understand himself better.
- **Rediscovering HOPE, before understanding PDA we felt so utterly hopeless, we have our bad days even now. But now we have HOPE. Hope that the meltdowns the behaviour the SEN needs, we will find a way of getting through this. One day at a time.**
- Having a very quirky, fun and entertaining Doctor Who expert in my family!

- So much love, trust, knowing I am doing everything I can to make things better for him. My child believing in me to help him.
- **Being able to understand my child**
- Realising I'm a stronger person than I thought I ever thought I could be
- **Unconditional love**
- Keeps me fit met some lovely parents
- **Sometimes my child wants a hug. These rare occasions are worth the heartache.**
- When they say they love us.

## Question 5: Is there anyone you would like to say “thank you” to?

- My husband!!!!
- Jackie Richardson and Emma Morris for setting up a parent support group they have helped me feel less isolated and alone.
- Miss Kate Westwood, SENCO at Heatherbrook Primary School, Leicester
- **Everyone at the PDA society and all the professionals working to get PDA recognised as a legitimate diagnosis**
- The general Parents of children with PDA community
- **Dr Beverley Steffert who has gone beyond original assessment/diagnosis to help us!**
- Support workers at carers in Bedfordshire and my local Parent partnership service.
- **God!**
- Jane Sherwin - I would not have been able to have got this far without her, she is amazing.
- **My inspirations have been Neville Starnes, Jane Sherwin and Trish Duffy (of the Dinky and Me blog). They have also become good friends and, indeed, colleagues in my PDA support efforts.**
- Facebook page and other PDA parents have made me realise it's not just us going through hell. PDA society website has been a wealth of information
- **The whole PDA army!!! If I'm ever feeling down there are hundreds of parents and PDAers on Facebook to remind me I'm not alone and i can keep going!!!**
- Mark and Jess Hughes put on a great course- they are lovely people and I would like them to know their help was much appreciated.
- **My family for their continued support.**
- Other parents
- **Karen Whichello for her informative PDA training and Jen Wilson, Specialist Speech and Language Therapist, Trafford Borough Council for her support in school and advice**

- **ADD-Vance - a charity in Herts that supports families living with ASD/ ADHD**
- "I have recently started working with Cathy May. This is being very useful as it give me time to reflect on what has gone on and how to tweak my approaches. Having someone with PDA experience, but who is not emotionally involved in your case, means that they can be more objective about situations. This helps you to be more reflective. It also helps you be more focused on those little targets.
- **So Yes, Thanks to people like Cathy May, Karen Whichello and anyone out there who is being a sounding board/ coach to listen and guide for parents and staff dealing with PDA individuals."**
- His teaching assistant Mrs Jamfar
- **His Teaching Assistant after diagnosis of PDA for her ingenuity and creativity in delivering the curriculum.**
- Buckinghamshire Learning Trust Early birds team Hayley Abel and Hil Haddock.
- **My mum! Whilst she didn't and doesn't understand PDA, her love and support helped me through when other friends and family were less than supportive**
- No, sorry.
- Judy Eaton, Private Clinical Psychologist. Mark and Ange Knowles and Paula Webb who ran the first parents course and educated us about PDA.
- **CAMHS Doncaster**
- Just to other parents/ carers for being so open on the support groups making it feel like a safe place to vent, laugh or cry
- **Our CAHMS councillor**
- Mick Rimmington who ran a course on behaviour that helped change our perception and understand the reasons behind the behaviours. PDA Facebook pages and the support and help from other parents who go through similar challenges and struggles. It's nice to be able to chat and vent in an understanding environment. And massive thanks to the PDA society website that is so informative on all areas of PDA and is a life line of information. Im looking forward to the conference thank you.

- "I would like to say thank you to our health visitor Jane, she was honest and supportive from the first day we had concerns about my son's development. Without her support we would be where we are today. She told me that I couldn't help him until I accepted his difficulties myself. She was right and those words gave me the strength to keep fighting for him. "
- **Julia Daunt and the PDA Society, Dr Jo Jones, Bedfordshire PDA Group, Sonia Owen - Action for Asperger's, Families in Focus, Autism Bedfordshire**
- That's a nice offer but it's also a bit weird so thank you but no thank you. :)
- **Challenging behaviour foundation**
- Add-Vance
- **Ruth Fidler and Pat Smith originally.**
- "Mrs Judith Smith SENCO at King Egbert's School
- **David Fong Clinical Psychologist and Nisha Alex at Centenary CAMHS Sheffield, David College support worker at school.**
- Tracey and Debra at Sheffield support group, Paula for running the Rotherham PDA course for parents"
- **Joolz Phillips- a best friend I've made since having my child who also has a child with PDA, I could not have coped and still wouldn't cope without her.**
- Blue Millicent Neville for many long conversations in the early days. They were my only source of information at the time.
- **Carol Ward from West Bridgford Nottingham for being a constant support**
- Jo Jones. She is amazing. Mark and Jessany Hughes for running a PDA course
- **My eldest daughter and son who have supported me caring for their sister.**
- Our speech therapist
- **PDA support group**
- Unfortunately, I have had to help myself in all of this so a big pat on the back goes to... 'Me'

- Julia Daunt and her fellow colleagues in the PDA Society; Dr Jo Jones and colleagues; Bedfordshire PDA Group; Dr Elizabeth Willer, GP, Highlands, Flitwick; Sonia Owen and Elaine Nicholson Action for Asperger's; Autism Bedfordshire; Sandra at PWhr; Families in Focus; The Maudsley.
- **Lewisham Police have helped with De-escalation. There should be other services available to help but there doesn't seem to be immediate response services apart from the police. Thank you to them.**
- Those few individuals that believed in us, you won't know their names - they won't be at the conference
- **Anyone and everyone who truly listened to our concerns and did not blame our parenting skills.**
- My mum. Jean Phillips who has been an amazing support through everything.
- **I won't know anyone at the conference but I have had help from the website of the Elizabeth Newton Centre which helped with practical advice 10 years ago.**
- Trace Mcquillian Smith, was the first person to recognise our struggle and point us in the direction of information...thank you so much Trace , best wishes ,
- **Jane Sherwin**
- The UK, NW & worldwide PDA sites. Support and understanding beyond. Jude Seaward - advice without judgement.
- **Fiona Slomovic SEN Advocate, Bridget McCabe counsellor**
- The Facebook PDA UK group and PDA (the lighter side). The support from everyone in those groups is fantastic, to the PDA society for providing all the information and help when needed. Maverick Television for helping us get a diagnosis as I dread to think where we would be now.
- **My husband for sticking it out with me**
- Not yet!
- **Friends and family (but won't be at conference).**
- Cathy May mentioned the possibility of the diagnosis and we would be on a different path if it weren't for her.

- Her p.a. Estelle
- **Phil Christie, Jane Sherwin for their writings**
- The support networks on the Facebook PDA groups.
- **Debbie Thelwell for her support and understanding.**
- The PDA society and other PDA parents I have met.
- **Moose, Webb and Debra from the forum for really helpful responses to posts. The other local parents I have met too.**
- Our EHCP Co-ordinator, Kim Breen, has been fantastic; an experienced head teacher before joining the LA she's advocated on our son's behalf, recognizing the primary school's inadequacy, and helped secure the best available educational provision possible.
- **The lead Senco at my sons school who told me about PDA it was a huge lightbulb moment!**
- Ron Fortuna @ Target Autism for recommending the conference to me and Educational Psychologist Kate Forder for her support.
- **Dr Jo Jones**
- All the staff at my son school NAS Robert Ogden school, without these people my son would be without an education
- **Lynda Ray - grandma, who showed me what it means to have unconditional love for your child.**
- Debbie West - For teaching me so much about PDA and for always being able to see things in a balanced way."
- "Gill Capaldi, at that time she was an Early Years Special Needs teacher who supported me to get the right nursery placement for my son, and to start the process of getting a statement of special educational needs.
- **Helen Gill, Speech and Language Therapist (time4talking) and Liz Watkins, Senior Occupational therapist who worked at Rotherham Child Development Centre, and along with a colleague first told us about PDA.**

- Dr Jacqueline Olurin-Lynch, consultant clinical psychologist who worked in a local team called S.T.E.P.S. and helped us to get a referral to ENC
- **My son's GP, Dr Byrne, who has been really supportive over the years to my family.**
- Mrs Collette Bartholomew, my son's keyworker throughout secondary school (see the workshop relating to mainstream school support!) plus many others!
- **My mother, Cecily Beard, for her acceptance of things she's not used to, and her unwavering support no matter what I come up with.**
- Kim Stephenson (although not sure if she'll be attending).
- **Jane Sherwin, who has helped so many of us along the way, and without her blog I would still be stuck in the wasteland.**
- "Neville, I think most of us have seen the videos. Those of us on the PDA forum will have had such positive support from knowing we aren't crap parents - this isn't us.
- **There's Debbie West as well. Awesome job Debbie!**
- Can't forget every other parent who has been brave enough to share their stories. In this world of social networking it has made it too easy to be judged so actually sharing the stories of the children the lives is a very brave thing to do. Thank you for being part of my support network. "
- **"Sue King - sensory bound**
- Debra West - listening, offering support and been so good at what she does"
- **Jane Sherwin. A HUGE thank you for your support and tireless work, all the while having a full plate of her own.**
- Jane Sherwin
- Our newly formed 'PDA Yorkshire' group is quickly becoming an amazing source of support. The small group of parents who support each other are invaluable
- **Margo Duncan. If Margo hadn't been inspired to take over the PDA Contact Group over 10 yrs. ago and create the PDA Society and raise so much Awareness of PDA, we would not be sitting here today. Thank you Margo, 10 yrs. ago it must have been a lonely uphill task but you have built something that will last and keep on growing."**