

# **PDA THOUGHTS – FOR SIBLINGS!**

## **Questions and answers about the PDA profile of autism for young people and siblings**

### **Introduction**

Our eldest daughter (14), has a sister (11) who was diagnosed with the PDA profile of autism in 2015. My family, our daughter and other families we know have often asked if there is a question and answer sheet about PDA specifically for young people and siblings. So, what follows are the initial key questions we found that our daughter wanted to know, although I am sure many others could be included.

### **I've been told my sibling has PDA; what does that mean?**

Pathological Demand Avoidance (PDA) is now increasingly recognised as a profile within the autism spectrum. This basically means that your brother or sister sees the world in a slightly different way to you, this causes anxiety and to manage this they need to be in control of every day expectations, situations and demands which helps reduce uncertainty. This is not something that happens occasionally but is there all the time, even if you can't physically see it. Avoiding demands, whether these are spoken or unspoken, is their coping mechanism, because their anxiety drives them to be in control; feeling more in control helps ease their anxiety.

They will also share similar differences with others on the autism spectrum too, which will mean they have difficulties with social interaction and communication. This may involve difficulties in understanding how they themselves feel and interpreting other people's responses. These types of difficulties could also mean that your sibling struggles to know what to do in a situation or how to act in a socially acceptable way. They may also show very repetitive patterns of behaviour, and have repetitive activities or interests.

Individuals with PDA (also known as PDAers) may have other overlapping diagnoses such as sensory processing differences, dyspraxia, dyslexia, ADHD, epilepsy, selective mutism, learning disabilities etc. These additional conditions will also affect how your sibling reacts and so you may wish to ask your family about additional conditions that your sibling may have to help your understanding.

### **Can I catch it?**

PDA is something that a person is born with, so no you can't catch it. It is a normal reaction to feel anxious when you are around another person who is anxious, but having these feelings doesn't necessarily mean that you have PDA. If you have any questions or concerns, it's always best to talk to your parents/guardian.

## **Will it go away?**

No, PDA is a lifelong condition. Hopefully your sibling will learn to understand more about their own needs as they grow and develop and it will become easier for them to understand and manage their own feelings and emotions as well as for you and your family.

## **My sibling looks just like other children; are you sure that he/she has PDA?**

PDA is not a physical disability, it is a developmental disability and so it affects how your sibling communicates and relates to other people, and how they experience the world in which they live. Autism is often called a “hidden disability” and some autistic people are able to hide or mask their emotions very well in public places (particularly at school), sometimes it is only when they feel they are in a safe environment (like at home) that they will release their emotions and show their anxieties to others. Being able to mask their difficulties and having surface sociability is very common for children with the PDA profile of autism.

## **Why does my sibling appear to have very different sides to their character and quick mood changes?**

PDA can affect people in different ways and for many PDAers they do appear to change their character and how they behave very quickly. You may hear people say they are like ‘Jekyll & Hyde’ or that their behaviour has changed like ‘a flick of a switch’ but what they mean is that there appears to be two different sides to their character. For PDAers, anxiety can rise so quickly and so high that the individual is unable to control their emotions and this is often released quickly with seemingly no warning. It may be in the form of physical aggression, violence, verbal abuse or the individual may become very quiet, withdrawn or run away. These emotions can equally disappear just as quickly as they are shown, particularly if distraction techniques have worked and the individual goes back to being calm and possibly even happy.

## **Why does my sibling want to be with me all the time and want to control everything that we do together?**

Children with different autism profiles often have obsessions with objects, facts and subjects e.g. cars and trains. Children with a PDA profile can also have similar obsessions, but they often focus on people to an obsessive level from either a love or hate perspective. Many PDAers like to spend their time with their brother or sister and want to do everything that they do, refusing to let them have time alone or give them any space. This may feel very overwhelming and stifling so please do talk to your parent/guardian about it to see if they can help negotiate some separation time for you.

## What is a panic attack or meltdown?

When a PDAer is unable to control their anxiety, this can cause them to have a panic attack which can take many forms. For example, one minute your brother or sister may be loving and happy, the next they could be kicking and screaming because their anxiety has risen so much that they have lost all control.

Your sibling might invade your personal space, try to take or break your possessions, show aggression, violence, verbal abuse, scream, try to hurt themselves or other such extreme behaviour. Some siblings may however show no extreme outbursts and may just withdraw into a quiet safe place, often with no communication and possibly, but not always, some form of stimming (doing something to give themselves a sensory input to help them feel calm i.e. rocking.) Occasionally a sibling may just withdraw and sleep.

A meltdown is basically the same as a panic attack; this is when anxiety and stress has reached such an extreme level that the individual is no longer in control of their behaviour or reactions. It is not a tantrum where they are aware of their surroundings and have control over their behaviour. During a meltdown, an individual may be unable to control what they are doing because they are often totally overwhelmed by their distress. It may sometimes look like they do have control, but they are not in control of their rising anxiety and are often unable to stop their actions because of this. They often may not remember what has happened afterwards or why they were upset. Sometimes they can show remorse and at other times they may not show any remorse or even understand why other people are upset. It may also take several hours for the individual to recover and feel calm again.

Try to remember that a panic attack/meltdown is not your fault, your sibling is just unable to cope in that moment with the world around them. There are many factors that can cause a meltdown; it may be because they have had too much stimulation, are experiencing sensory overload, may feel that they are losing control over a game or have got frustrated or over-excited to name just a few. It is important to try to remember that they will still love you and it will not be their conscious intention to hurt you or your family.

## How can I help?

Trying to **remain calm** at all times and thinking about the **tone of voice** you use can help to keep your sibling calm. As soon as you raise your voice they may begin to feel anxious and this could result in them reacting in a protective and defensive manner which may involve them beginning to shout or switch off, both of which could mean that they won't be able to listen or hear what you are actually trying to say.

Using **appropriate vocabulary** that isn't threatening or demanding also helps. This includes trying to avoid words like 'no' or 'stop' as these are considered demands. Similar words to avoid include: need, must, must not, will, won't, can't, now and by (time/date).

Instead try to be creative and say something like 'if you want we can...' or 'how do you feel about playing/doing... with me'. This will help your sibling feel that they have some control and choice over these decisions.

So, for example, if your brother or sister takes something that you don't want them to have, trying to grab it back or shouting at them not to take it, is not necessarily going to work and may encourage them to hold it tighter or destroy it. This can be hard, but if you can try to offer an alternative item or negotiate a swap, a better outcome may be achieved. Asking your parents/guardian to help may also be the best thing to do, so keep talking to them and ask them for their advice on what they think works best with your sibling.

Younger children, in particular, often like to have **rices** to complete things, so saying things like 'bet you can't put your shoes on before me?', 'race you upstairs' or 'I'm sure I'll be ready for bed before you' can be good, but remember, they also like to win!

As you are beginning to understand, PDAers do not like being told what to do because this is a demand, so **offering choices** and asking them to choose can often help; shall we play in the garden or indoors? Would you like to play with me now or later? Your sibling may need to choose the game you play or the way you spend time together. Remember not to offer too many choices. You may also find that as the PDAer gets older choices can become too much; they want to be able to choose but they then worry that they're going to make the wrong choice, so at this point you might then be able to say for example "well let's try this first and we can do xxx later", etc.

Older children also like choices and **humour** can often help in situations too; 'oh silly me I put my shoes on the wrong feet!', or just something like blowing raspberries and telling jokes.

**Distraction** is widely used for all children, which means trying to engage them in something different to what is causing them to be anxious. Calming activities like blowing bubbles, having a drink through a straw or chewing something can also help. Talking to them through a favourite toy or using silly voices can be pretty good too.

Many PDAers will try to **negotiate** if they don't want to do something or want to change the boundaries so be prepared to enter into a discussion. For example, your sibling may ask if you can play with them and you may want to but know you have homework to do, so try something like "I have some homework for school but yes I'd like to play with you for 15 minutes first" they may say "No, an hour", you could then say "I'm sorry I should finish my work, how about we play for 20 minutes or we could have 15 minutes now and then some more time later?" Hopefully you get the idea.

PDAers may also pretend that they can't move or hear you if they don't want to do something. They can shout and keep repeating things until you give in too! Therefore, try to **change your approach** if this happens rather than carrying on with what you are doing.

By now you're probably thinking that this is too much and you will never remember what to do, but don't worry. As you learn more about your sibling and how they interact with you, you will find the strategies and techniques that work. If you forget and your sibling gets anxious or has a panic attack, **don't panic yourself**, just keep doing your best, consider calling for your parent/guardian but remember **we all make mistakes** and forget things; living with PDA is challenging and can feel very complex. Your family will undoubtedly be appreciative that you are trying and as a sibling you may find you actually find it easier than your parents/guardian!

Finally, remember to **listen** to your family, particularly if they ask you to help with your sibling in a certain way or not to talk at a given time. There will be a reason for this and perhaps one that you yourself may not have anticipated or foreseen, so trust that they have your best interests at heart as well as your siblings, they will want to keep you safe. Your family will probably have to do lots of **advance planning** whether this is for outings, visits to friends or family, attending appointments, holidays, etc. Spur of the moment activities and play dates may be difficult to do and it could even be that you begin to feel left out or ignored, particularly when your family are dealing with a panic attack. However, try not to get frustrated or angry, even though it may not feel fair. **Talk to your family**, explain how you feel and decide together how you can all make things work better.

## **Why does my sibling have different rules to me?**

Parents/guardians often have to make decisions that can on the surface seem unfair. Looking after a child with a PDA profile can be very challenging and it is not always possible to achieve compliance, so families may choose the battles they wish to fight. This means that your sibling may appear to get away with something that you wouldn't.

For example, your sibling may stand on a table when they are upset, but they are ignored because the consequence of getting them down could be worse, for example they might hit you. However if you choose to act in this way it's likely that the 'socially acceptable norm' of not standing on a table would be enforced by your parents.

Another example could be that you both have a set bedtime but your sibling wants more time before they go up. You understand that you need to follow the house rules and should do as you have been asked, but for your sibling this is a demand, so a little bit of negotiation may be needed which results in a little more time, to ensure they do go to bed rather than your family completely refusing the request which could lead to an immediate panic attack.

## **Are my emotions normal?**

There will probably be many occasions where you may feel you have had to put your sibling's needs first, relent and be compliant and it just doesn't seem fair. This is normal. You may also start to feel very negative and unsure about things, as your emotions will be affected by your sibling's behaviour and by the reactions of others too. It is natural that you may feel: angry, frustrated, scared, unhappy, unloved, bullied, embarrassed, etc.

You may also feel resentment towards your sibling, want to retaliate against their behaviour or just feel depressed.

However it is vitally important that you tell someone how you feel and the best people are your parents/guardians. If for whatever reason you don't feel comfortable doing this, you could also share your feelings with a grandparent/uncle/aunt, a teacher, your doctor or contact a support line. Some of the organisations that may be able to offer you some help and support can be found below.

<https://www.youngsibs.org.uk/>

<https://www.siblingsupport.org/>

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

<http://www.youngminds.org.uk/>

<https://carers.org/article/getting-support-if-you-are-young-carer-or-young-adult-carer>

<https://childline.org.uk/>

## **Should I tell my friends my sibling has PDA?**

This is entirely up to you and your family. Friends play an important part in our life so talking and sharing with them about your family can be really helpful, especially if you would like them to visit your home and meet your sibling.

## **Is there any more information?**

You may still have lots of questions, particularly if your sibling has other conditions as well as the PDA profile of autism. As discussed throughout this information sheet, your parents/guardians are the best people to talk to because they will understand your sibling and be able to share with you and talk about specific strategies and ideas for your brother or sister. Please don't be afraid to share your concerns with them, they will want to help you.

There is also a good book specifically written for young people about PDA that you may find helpful to read: 'Can I tell you about pathological demand avoidance syndrome?' by Ruth Fidler & Phil Christie (age 7+) <https://www.amazon.co.uk/about-Pathological-Demand-Avoidance-syndrome/dp/1849055130>

Autism East Midlands has also published a book specifically for the siblings of children with PDA 'Children with Pathological Demand Avoidance Syndrome (PDA) a booklet for brother and sisters' This book can be ordered from the Autism East Midlands Diagnostic Centre, Tel no: 0115 9609263 email: [diagnostic-centre@autismeastmidlands.org.uk](mailto:diagnostic-centre@autismeastmidlands.org.uk)

Please remember to get your parent/guardian's permission before placing an order for any book.

## **Final Thoughts**

Living with a sibling who has the PDA profile of autism requires a lot of creativity and patience, it can feel like an emotional roller-coaster ride, that you're constantly walking on eggshells and that life is just not fair. But remember there are many people who can support you too; try not to keep secrets, share your feelings and work as part of a team with your family in the knowledge that they will look after you too.

Your sibling is probably one of the most precious people in your life so find ways to be with them that are non-threatening and that avoid most demands. Remember that PDA is just a part of your sibling, they will also have many wonderful strengths, interests and passions; try to use these to your advantage, and you'll soon be building supportive, trusting and loving relationships with each other! Finally, and perhaps most importantly, cherish and enjoy the time that you share with your sibling!

Please do remember that the thoughts shared here relate to our own personal circumstances and are questions that our daughter or friends have raised with us. We hope that our experiences may be useful for other families, however we acknowledge that every family will have varying family dynamics and difficulties to deal with that may require alternative approaches depending on the unique needs of the PDAer and the unique needs of their siblings and family.

## **Information for parents**

For more information about the diagnostic criteria and professional understanding of PDA please visit <http://www.autism.org.uk/PDA>.

Additional information and resources can also be found via The PDA Society <http://www.pdasociety.org.uk>.

Finally, I have also written another information sheet based on our own personal experiences:

“PDA Thoughts! How PDA presents and affects our daughter, the impact on family and the strategies that we find successful”

If you would just like to know more, please contact me via the South Bucks PDA Support Group: [PDAGroup@harveys-home.me.uk](mailto:PDAGroup@harveys-home.me.uk).

## **With many thanks to**

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***Hilary Harvey – Revised Nov 2019***