

PACE & The Elephant in the Room



A resource to support the webinar delivered by Nicola Reekie Endings, Beginnings & The Elephant in the Room

> August 2023 for The PDA Space Portal (www.thepdaspace.com)



Created by Helen Edgar

Multiplex Families

Danielle Jata-Hall (<u>PDA Parenting</u>) coined the phrase 'multiplex families' to describe the many different needs of families that are multiply neurodivergent (where parents/carers are neurodivergent and also their children).

Many families are negotiating the complexities of Autism, PDA, ADHD, OCD and other neurodivergences with their children and juggling their own needs.

It can be really difficult and exhausting being a parent/ carer. You may feel isolated and misunderstood and need help figuring out where to turn or what to do.

You may feel injustice in how difficult your family life is and feel like others are judging you for having to do things differently.

Remember, you are not alone. There is a beautiful community of multiplex, multiply neurodivergent families here. The PDA Space supports you and your family through this journey.

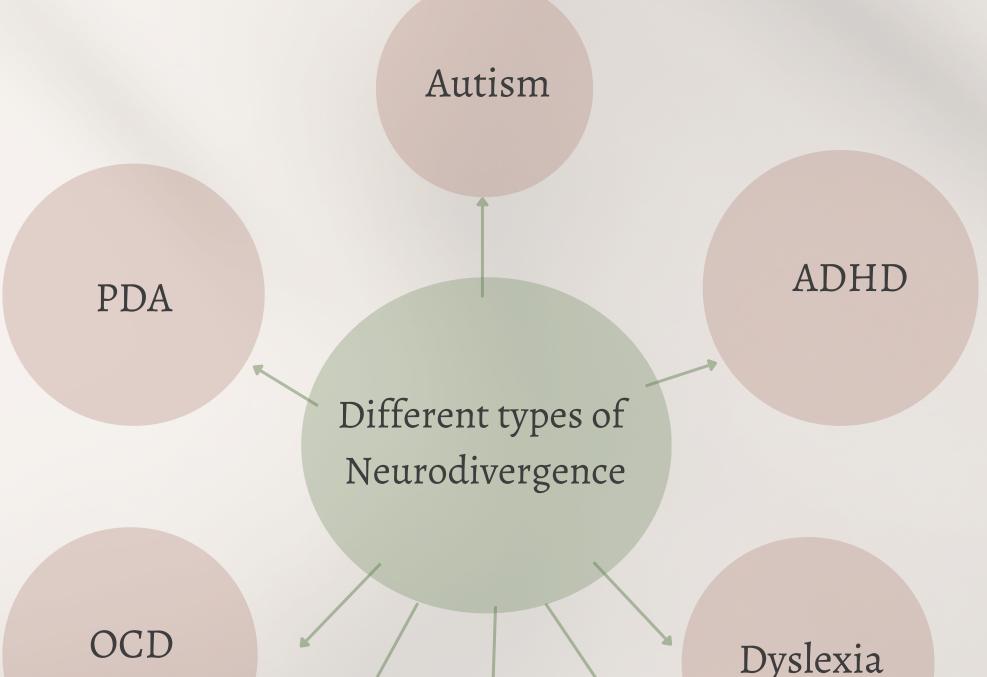
We know that having conversations with our children can be difficult. We will look at PACE* as a way to communicate and discuss 'the elephant in the room'.

*PACE is an approach developed by <u>Dr Dan Hughes</u>, an American psychologist. PACE stands for Playfulness, Acceptance, Curiosity and Empathy. The PDA Space has adapted this model to reflect the needs of the families in our community.



Neurodivergent Families

These are examples of different types of neurodivergence. This list is not exhaustive and many people are multiply neurodivergent. Many families have lots of differences to navigate that may further impact mental and physical health for the whole family.



PDA

Sensory Processing Differences

Dyspraxia

Bi-Polar





Endings & Beginnings

Holidays can create uncertainty as your usual dependable routines and ways of living suddenly change. You may feel that as soon as you have settled into your new routine, it is time to start thinking about transitioning and preparing for the end of the holiday and another new beginning.

Research from <u>The PDA Society 'Being Misunderstood in</u> <u>Education'</u> report (2018) showed that up to 70% of PDAers are either not in school or struggle to attend on a regular basis.

This may mean that a 'new term' for your PDA child is not filled with the excitement of buying a new uniform. Instead, you may feel your family life is filled with uncertainty, stress and anxiety for your child and also for you as a parent/carer.

There can be added stress and difficulties if you have more than one child. One child may have appropriate educational provision, and another may not, or you may have different types of settings and provision going on to try and navigate. You may be juggling many different needs and continuing to fight for an EHCP. Siblings may feel it is unfair that things aren't the same for them, which can create added challenges. Some families opt to go down the home education route, and many may be in limbo -neither able to home educate and still not accessing appropriate provision. The PDA Space community understands the difficult paths families have to navigate, and we aim to support you on this journey.





The Elephant in the Room

It can help everyone if you open conversations and discuss difficulties and concerns. If you or your child has a PDA profile, it may sometimes feel easier to avoid some topics of conversation and not talk about 'the elephant in the room'. It can feel easier to avoid any potential confrontation or risk further upset, but not talking can create added stress and make that elephant feel even bigger over time.

Everyone benefits from feeling that they are in a safe space and feeling understood. It is important to feel nurtured and for feelings to be validated. It can help to have some of those more tricky conversations and to acknowledge when your children may feel upset, angry, disappointed, sad or frustrated. They may think their life is unfair and may feel very different from some of their friends.

Family life can sometimes be even more challenging if siblings all have different needs. If some siblings have educational provisions and others are still in limbo and may be at home, this can cause tension in the family and also with friends.

Talking helps, but direct demands and conversations can be tricky, as we know for PDAers! Weaving low-demand chat into play situations and following their lead is a way around this and using PACE.





Family Planning

We want to share some ideas to help make life a bit easier. It can help to plan together as a family to ensure everyone feels they are being listened to and have an input into family life.

Remember, sometimes doing less can be more helpful when you have many different sensory and neurodivergent needs to account for. It can help to PACE everyone's needs and have lots of time around events to rest and recharge in their way.

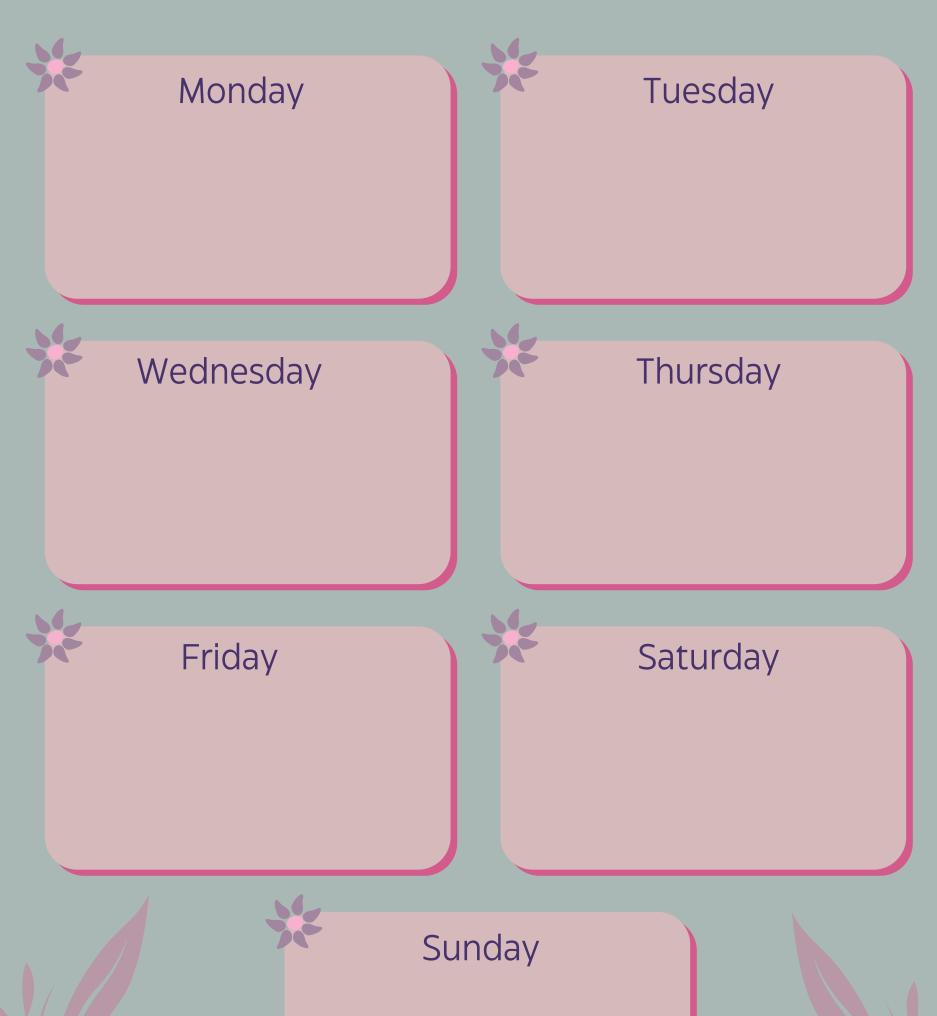
We have included a weekly planner on the next page. It can be helpful for children to have their own planners to refer to; you could use pictures instead of words or even have a family-shared calendar. The important thing is that everyone feels they have some autonomy and control and input into their own life, so everyone feels their needs are validated and that they are being listened to.

As well as planning the bigger and more significant events and appointments, it helps to prepare for other changes that might be coming up subtly. Even little things like pre-washing the school uniform and hanging it up on the line two weeks before school can help drip-feed the idea that things are going to start changing. It can be a subtle way, low-demand way of casually opening up conversations.





Weekly Planner



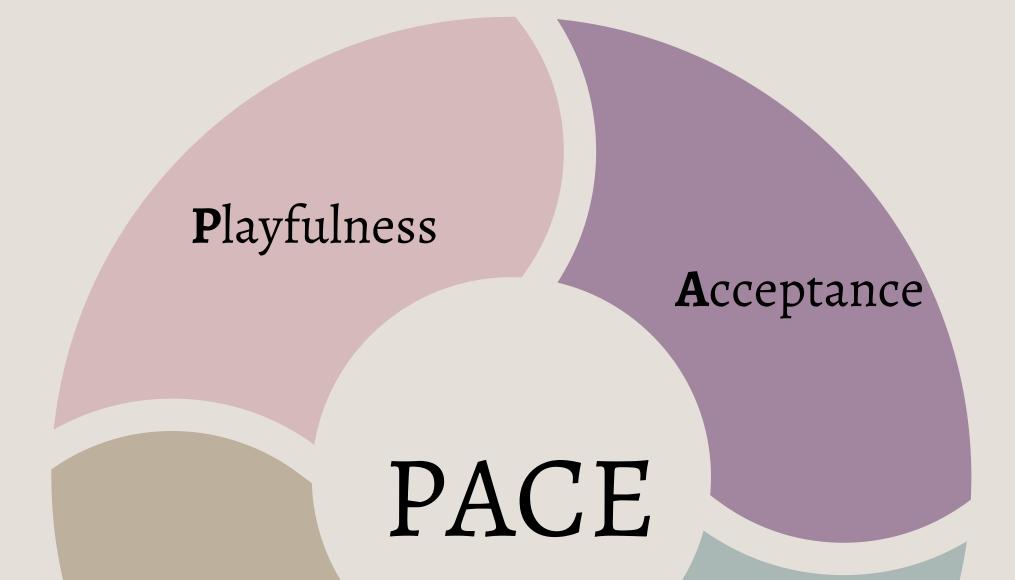






PACE your Family Needs

*PACE is an approach developed by <u>Dr Dan Hughes</u>, an American psychologist. The original PACE acronym stands for Playfulness, Acceptance, Curiosity and Empathy. The PDA Space has adapted this model to reflect the needs of the families in our community and included 'Compassion'.





Compassion





PACE your Family Needs

P

Playfulness - having fun and weaving conversations into play can help PDAers who may find direct demands and conversations difficult. Play shows you are interested, intune and have time for each other.

A

Acceptance - means validating emotions. Being accepting of feelings does not mean you have to accept unwanted behaviour but you can acknowledge their difficult feelings and show empathy. You can try and connect without judgement. Together you can work through the difficult moment, holding their space and giving time.

С

Compassion - this is also self compassion for you as a parent too! Remember to try and treat yourself with the same kindness that you show to your children. Give yourself time and model ways that you look after yourself. Remember you can't pour from an empty cup!

E

Empathy - showing empathy is a way of demonstrating to your child that you are there with them and are trying to understand their difficulty. It helps to strengthen your relationship, increasing trust and safety can help to reduce anxiety.

We know that talking about the 'elephant' in the room' is never easy. We hope PACE may be a useful tool for you and your family to help your child feel safe and enable ways to communicate those tricky conversations. Please join The PDA Space for further information and a warm welcome from our wonderful supportive community.



Signposting



www.thepdaspace.com Family support workshops, webinars, coaching and online peer support groups



www.autismunderstood.co.uk Website designed by autistic young people, for autistic people



www.autisticparentsuk.org Autistic Parent network offering peer support



www.pdasociety.org.uk PDA Society UK

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www.pdaparenting.com PDA Parenting website

www.autisticrealms.com Autism/ education and mental health articles and resources

Please seek professional advice if needed.





A free community resource to support the webinar delivered by

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