

## Newsletter Number 7 (Spring 2024)

Welcome to our quarterly Newsletter for families who are on our neurodevelopmental assessment pathway. This on-line newsletter contains useful information, links and updates from the team which may be useful while you are waiting for the assessment process to begin.

Previous copies of the newsletter are available on the resources page at <https://theautismnetwork.co.uk>

### PDA

Pathological Demand Avoidance (PDA) is widely understood to be a profile on the autism spectrum, though we are still at an early stage in understanding and research of PDA. We know autism is dimensional - it involves complex patterns of overlapping strengths, differences and challenges that are different in individuals and in different environments.

The PDA profile of autism means that an individual will share many autistic characteristics including significant sensory experience differences.

and in addition:

- Have a need for control which is often anxiety related
- Experiences intense emotions and mood swings
- Are driven to avoid everyday demands and expectations (including things that the individual wants to do and enjoys) to an extreme extent
- Tend to use approaches that are 'social' in nature to avoid demands
- Tend not to respond to conventional parenting, teaching or support approached

Adapted from the PDA society website which has a lot of useful information and advice.

[www.pdasociety.org.uk](http://www.pdasociety.org.uk)

### Understanding my autism -A programme for older autistic adults

The Autism Network has secured funding from the Adult Autism Fund for a post-diagnosis information and support programme. The project is to develop and pilot a programme specifically for those who have been diagnosed later in life (50+).

A formal diagnosis is not required and those who are self-identifying as autistic are welcome.

The on-line programme will take the form of a weekly session for 1 ½ hours for 6 weeks. Dates and times will be arranged from April onwards.

If you know of anyone who may be interested in participating they can contact The Autism Network on [info@theautismnetwork.co.uk](mailto:info@theautismnetwork.co.uk)

## Autism and the Weather

Although we love to moan about the weather, rarely do we reflect on if and how it actually affects us. For an autistic child there may be psychological and physical impacts that we don't notice or don't attribute to the daily changes in weather.

Firstly there is the sensory impact of the differences in hot, windy or cold. It's not always easy to see a sensory trigger and the weather might be just another challenge that contributes to sensory overload.

Secondly, you might have noticed that the weather can be unpredictable. It can intrude on the most carefully planned activity. Sudden unexpected changes are difficult for an autistic child and may be harder to understand if the weather related reason is not obvious ('heavy snow is forecast'!)

Finally there is some research that shows changes in atmospheric pressure can affect autistic people. When the air pressure is high, we have dry, sunny weather; when pressure is low, rain and dark clouds. A drop in air pressure can lead to a slight drop in blood oxygen levels that most of us are unaware of. However, our bodies adjust our heart rate and blood pressure to adapt, This in turn could interfere with brain activity and possible changes in mood and sense of well being.

'So what...?' you might think 'we can't change the weather'

No but you could:

- Make it a topic of conversation – can it be used as a reason to communicate
- Can you use the weather to teach about mood and feelings?
- Encourage weather awareness, make recordings and measurements– does your child like numbers, charts, they joy of a spreadsheet?
- Do your planned activities with an autistic child need a well rehearsed Plan B in case of weather changes
- Be aware of how the weather impacts on your own mood and activity and how do you cope with those. Then think about how the weather impacts on your autistic child. It might not be obvious but it might be worth thinking about.

## Autism and the vestibular system (sense of balance)

We often forget that an autistic child's sense of balance might be different.

**Over responsive:** might seem to experience motor sickness or vertigo and dislikes activities involving lots of movement.

**Under responsive:** seeks out activity with lots of movement, loves fairground rides, swings and might appear to be hyperactive.

**Question:**

Is it exhausting processing all that sensory input?

**Answer:**

As an autistic person, I find it nigh on impossible to filter out sensory input. My brain is constantly processing the noises, smells, touches often long after contact ended. This can be exhausting, yes. But that's not the whole story. Sensory input can also be really comforting too. Good sensory input can be really energising, soothing, comforting too. It's not just about avoiding sensory inputs that hurt or exhaust us. It's about getting the right sensory balances. That helps me sense when I need food, regulate my emotions, energise me.

Too much understanding of autistic sensory processing is about avoidance when that's only half the story. The right input at the right time can be a real game changer. So I'm off for a hot cup of tea, listen to some favourite music and grab a fidget tool.

Contribution from Marion McLaughlin Autistic advocate

<https://www.linkedin.com/in/marion-mclaughlin-21a086193/>

**Helpline for parents of children on the Neurodevelopmental Assessment Pathway**

The Autism Network has been commissioned by Fife HSCP to support families who are on the Neurodevelopmental Assessment Pathway.

Details about The Autism Network and the team can be found on their website :

<https://theautismnetwork.co.uk>

Although they don't have details about the waiting list for the assessment, they may be able to provide information that would be useful for you or signpost to another source of help. Sometimes it's just good to talk to someone who has the time to listen and to share your concerns and challenges.

To contact the Helpline call: 07706 012967. The helpline is not manned at any specific times but if you leave a message they will get back to you.

You can also email them at [info@theautismnetwork.co.uk](mailto:info@theautismnetwork.co.uk) and in your message let them know you are contacting the Fife Helpline.