

Autism and Anxiety: What helps?



June 7, 2019 By [Angela Kelly](#)

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Anxiety appears to be increasing in children in recent years, or is it perhaps that we just appreciate its existence more these days than when I was a child? Whatever the reason, more awareness means parents, schools and the medical profession are better placed to recognise it and hopefully help our children also to recognise it and manage their anxious feelings.

Additionally, anxiety in autism is now being understood and accepted as a separate condition. This is good news for many autistic individuals who have battled to get help for anxiety in the past only to be told, "Anxiety is a part of being autistic," or "You're autistic, what do you expect?" This happened to me when I asked for help for my son, so I have no doubt it will have happened to others too.

A new guide to help

Therefore it may be good news to learn that [City, University of London](#) [have produced a guide together](#) with West Sussex County Council's Autism and Social Communication team that says just that: Being autistic does not have to equate to being anxious and the two are separate and distinct from each other, but often co-morbid (co-existing). The guide suggests it will help teachers and other professionals understand the mental health needs of the children they support.

They write:

“The aim of our guide is to help teachers and other professionals better understand why certain strategies are often effective in helping children manage their emotions, why the same strategies might not always work, and what other strategies might be explored. Ultimately

we want to help professionals make informed decisions on how best to support individual children”

An evidence based guide to anxiety in autism. Sebastian B Gaigg, Autism Research Group City, University of London, Jane Crawford, Autism and Social Communication Team West Sussex County Council, Helen Cottell, Autism and Social Communication Team West Sussex County Council

They continue that the purpose of producing the guide, which they describe as 'unique and concise', is evidence-based and is being delivered to every school in West Sussex. It does contain a wealth of peer-reviewed referenced information and researched evidence, some as recent as 2017, plus the booklet itself is a handy A5 size, and not too wordy, which I really liked. [It is also downloadable](#) (PDF).

My son's anxiety is at times profound, so a guide like this to remind me how to help him would, I thought, be very helpful, even though I'm a therapist myself, working with young people with autism, PDA and anxiety among other conditions. But I'm also human and can struggle to remember in the moment how to help him to help himself.

Don't take it too literally...

On the whole, the guide provides a valuable insight into autistic anxiety from the neurotypical perspective. However, I am concerned that non-autistic people supporting autistic individuals, could risk taking the information too literally and apply it too widely as a one-size-fits-all, (ironic considering autistic individuals are the ones considered inflexible). What would be more useful would be to suggest that it's ONLY a guide, and that the individual's particular needs and personality should be the first and foremost consideration in providing the most appropriate support. Most autistic individuals that I know respond really well if you actually ask them what they need to help them!

Daily little traumas

Being autistic in a predominately neurotypical world can, for many individuals, be traumatising. Not in the classic way that people assume 'Trauma' to be, but in a small 't' kind of trauma'. Typically, people associate trauma to be things like a car crash, a violent assault, or experiencing or witnessing these things. But there are also many things that can and do make being alive on a day to day basis, traumatic.

Having these experiences will definitely increase an individual's anxiety and this is not included in the guide at all. Things like trying to understand neurotypical context, attend social functions, move house, or manage endings in relationships. Endings are not just things like divorce and death, for example, but might be a change in taxi driver or escort for school, a teacher off sick, managing the nuances of friendship, a beloved toy that is broken... This are just a few examples, but all these things potentially reinforce the feeling that the world is an unsafe place to be.

If a child (autistic or otherwise) does not feel safe, then their anxiety is more likely to be high; Meaning they are only able to access the survival part of their brain, the part responsible for flight, fight, and freeze responses. Beacon House has this insightful video clip explaining trauma.

Masking hides a freeze

Emerging research is suggesting that children who 'mask' their autism may well be operating in 'freeze' mode for a high proportion of their day as part of a coping strategy. Award winning academic Luke Beardon also talks of the trauma autistic children experience in his Podcast ['Three golden rules for supporting autistic pupils'](#). Well-supported autistic children will be less likely to develop anxiety or other mental health problems. It isn't rocket science!

The helpful aspects of the guide include highlighting that autism and anxiety are separate conditions and that overshadowing (assuming that being autistic means being anxious), is not useful in supporting autistic children. The information about the sensory profiles of autistic children is also helpful as it demonstrates how brains interpret some sensory

information and why autistic children may have sensory difficulties in school settings.

[Alexithymia](#) is brought to the forefront—a little known and often misunderstood condition—and I feel this is a very positive aspect of the guide. Alexithymia means a person is unable to identify what emotions they may be feeling. Informing those who support autistic children that there is a 50% possibility that the child they are supporting also has alexithymia. It can help them understand why a child may behave in a way others cannot understand and what they need to do to help. Ideally this would include creating a toolbox with the child when they are calm that will support them when difficult feelings arise and anxiety is escalating.

The additional resources and further reading is also very helpful. Remember, knowledge is power and the more you know the child, the more you will know how to help them.



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What doesn't work

The aspects of the guide that I felt were not representing the autistic community's experience of anxiety (based on my experience both academically, professionally and personally), were reference to what was

referred to as 'maladaptive' or 'idiosyncratic' responses to situations. While again, it's only a guide and impossible to include everything known about autism, it was disappointing that the writers chose refer to autism in this 'othering' and negative way.

In particular, I struggled with the example used in the guide about the 'happy birthday' song raising anxiety being 'highly idiosyncratic'. Why is this idiosyncratic? Unless you're comparing the autistic individual with a non-autistic peer, and why would you do that?

Let me explain my opinion: The Happy Birthday song is often sung loudly, out of tune, and has certain expectations of blowing out candles and showing gratitude for the birthday celebrations whilst being the centre of attention. Both my boys hate it and we no longer sing it on their birthdays – it really is no big deal when respecting a person's needs and validating them. Although my boys are autistic, it's not an exclusively autistic thing to loathe the song, or have a strong reaction to loud noise, or to being the centre of attention. And as another example, many neurotypicals are scared of spiders or insects despite the fact that most are not harmful, but a strong reaction is not considered 'idiosyncratic' or 'maladaptive' because they're not autistic, just 'regular humans'.

Finally, autistic individuals may experience excessive fear of unusual and highly idiosyncratic objects or events (e.g., the happy birthday song, TV sets or walking through doors) that would not commonly be associated with a specific phobia.

An Evidence Based Guide to Anxiety in Autism

Sensory processing was covered in reasonable detail, but [interoception](#) was omitted and this is such a significant aspect of autism. If you cannot identify your bodily sensations such as hot, cold, hungry, full, thirsty, needing the toilet or whether you are feeling a feeling or a bodily sensation then it is likely you are going to be at a disadvantage to interpret anxiety which in turn is likely to increase anxiety and this is so important for those supporting anxious autistic children to appreciate.

Interoception is a lesser-known sense that helps you understand and feel what's going on inside your body.

Kids who struggle with the interoceptive sense may have trouble knowing when they feel hungry, full, hot, cold or thirsty. Having trouble with this sense can also make self-regulation a challenge.

Interoception and Sensory Processing Issues: What You Need to Know By Amanda Morin

When thinking about which approaches to use to support the reduction of anxiety, those listed in the guide are often considered the most helpful, for example, mindfulness or CBT. They can be to both autistic and non-autistic children. However, this is again presented from the non-autistic perspective. What I have found in my work is explicitly explaining how the therapies work really helps, especially if it is delivered in a way that appreciates the impact of the child's autism. Then ask or communicate to the young person about what they want to achieve by coming for sessions, rather than assuming. This is often the most effective method.

Listening is the best technique

To be heard, understood and validated is often the most important part of any educational or therapeutic intervention. A concept that I found very interesting which was researched by Luke Beardson and Julia Leatherland an academic and parent of autistic children is the [Facts About Me](#) (FAMe™) theory (link is a pdf). Its aim is engaging autistic children and older students so they can share some of the difficulties they experience that create anxiety for them. Some examples of what the students shared were;

- Please break down my instructions for me – I can't take in a lot of information at one time,
- Please check that I have understood the task before I start
- Please write my homework down for me in my planner / provide me with a homework sheet
- Please only ask me to speak in front of the class if I put my hand up

to show I am happy to do so,

- Please help me find a group to work with – I find the activity of getting into groups difficult and stressful

This is then stored electronically so that it can be shared by all teaching staff to ensure optimum understanding and support. I cannot think of a better more effective way of supporting an autistic student than to help them communicate what it is that created the anxiety and would suggest that this piece of [research](#) is shared widely.

To conclude, the most effective way to reduce anxiety for autistic children is to listen to them. Listen to what they are telling you either in their behaviour, their voices or their words. If you are struggling with this then find an autistic advocate to help. This will provide you with the most valuable information to enable you to provide support. Don't assume that one method will work with all autistic children and don't assume all autistic children are the same. Be kind, be compassionate, listen and try to understand. This is the greatest anxiety reducer there is, honestly!

Also read:

- [Introducing FAME™: Can improved teacher access to individualised classroom support information impact positively on levels of anxiety in autistic pupils?](#)
- [Our magical mystery tour helped our autistic son deal with anxiety](#)
- [Book reviews: Kids in the Syndrome Mix and All Birds Have Anxiety](#)
- [Selective Mutism: When anxiety shuts down the power to speak](#)
- [Cognitive Behavioural Therapy for anxiety in youth with an autism spectrum disorder](#)
- [To medicate my anxious child or not. It's an emotive question](#)
- [Help! I'm a parent carer and I'm on my VERY last nerve!](#)
- [How can children be traumatised just by going to school?](#)

Don't miss a thing!