

Norfolk & Waveney
ASD/ADHD Support
Service February
2021

Dear Families......it has been a tough few months for all parents but for parents or carers of children and young people with an underlying neurodevelopmental disorder it has been even more challenging. You have children who are hardwired to dislike change, who love routine and who are inclined to compartmentalise the different areas of their lives, ie, 'Why do I have to listen to you talking about Maths? You are not a teacher!!!' Add to this the fact that

you are not getting a chance to recharge your own batteries because, in many cases, you have them at home 24/7. But stay strong. It can't last forever......can it? This issue of the Newsletter is going to focus on something that most of you will be familiar with.......

Let's take a moment to think about the bucket model of behaviour, which you will be familiar with if you have been on any of our courses or workshops.

This model is based on the concept that we all have a bucket in our heads which is filling up during the day with the many frustrations and pressures that we have to deal with. Having additional needs can mean that our children or young people have a bucket which is filling up pretty quickly. We can try to make holes in the bottom of the bucket for them by using a range of strategies to help them feel more calm and in control, such as structure and routine, managing change and reducing sensory input. Despite our best efforts however, there will be times when that bucket overflows, it cannot hold one more drip, and that is when we have to deal with a meltdown.

This model is

useful because it helps explain why sometimes our children or young people seem to go from zero to nuclear in about 10 seconds. Fusilli on your plate when you really like penne pasta, can be the drip in the bucket which makes it overflow. The idea of the bucket, and how full it may be at a given time, also helps us understand why a child may cope with something one day but not the next. When your child copes with the school bell ringing most days, but on this day runs from the classroom

screaming and tries to scale the perimeter fence, some may feel that this proves they are 'choosing the behaviour' when, in fact, on the day in question, the bell was probably just the final drip which made the bucket overflow. There are three stages to consider in a full blown ASD or ADHD meltdown............



The Build-Up Stage	Proactive Strategies (Despite doing all the things you normally do to maintain calm, you can see that things are heading towards a meltdown. There may still be time to head it off!)	Interrupt a behaviour which is causing frustration or anger, distract but then divert to a calmer activity rather than leaving to their own devices. Use their special interest to your advantage, ask a question, have a book handy, put on a dvd they like. Think about having a planned de-escalation script. 'I can see that you are getting upset, I want to help, if you can calm yourself a little, we can sort this out together'. Encourage them to take themselves to their safe space. Tell them what to do rather than what to stop doing. ('Stop screaming' to 'Let me see you take deep breaths') Your attention and when you give it and remove it is a powerful tool. Stay calm, because they have lost it does not mean you have to, shouting is the opposite of helpful. Think about your body language, try to maintain a deescalation stance and distance from them. Not too many questions or talking generally — agreed hand signals for 'calm down' or 'volume down' can be useful when they are no longer hearing you. Don't try to stop repetitive behaviours which they are using as a calming mechanism unless unsafe.
The Meltdown Stage	Reactive Strategies (Despite your best efforts, the meltdown is in full flow or maybe you did not even get the time to take some steps to avoid it)	Don't try to reason with them, they are beyond reason. Remember, not a tantrum but a complete loss of control. Don't restrain them unless absolutely necessary. Give them space but check on them regularly. Try to have empathy – remember that the most challenging behaviour is the most distressed behaviour. Give praise for the first signs that they are calming down despite what has come before.
The Aftermath	Restorative Strategies (This is important for the child and for family relationships)	Avoid recrimination – try to adopt a 'fresh start' policy. Allow them to sleep or zone out as they recover. Do not try to talk about what happened too soon as you could trigger another meltdown. When you can talk, ask how they felt just before. It is important that they begin to recognise the signs themselves and make links. Try to establish the trigger so you can avoid in future. Believe them when they say they cannot remember it when you do want to talk. It is probably true. Forcing them to say 'I am sorry' should not be your goal. Don't make them feel unloved or unlovable for something they are really not in control of.

FOR MORE INFORMATION ON MELTDOWNS JOIN US ON ZOOM AT OUR FEBRUARY INFORMATION SESSION. FULL DETAILS BELOW.



Our January Information Session for Families was on **EHCPs**. Thank you to everybody who joined us on Zoom for this enjoyable session. For those of you who could not join us, let's repeat some key points.

- Education, Health and Care Plans were designed for those with the most complex needs, those well behind their peers despite planned interventions and those who may require specialist provision at some stage.
- The key benefit is that the provision described in the plan becomes a legal requirement, it cannot be removed because a member of staff leaves or a child with greater needs joins the school.
- It has to be reviewed anually to ensure is fit for purpose and can continue until the age of 25 years, supporting transition even into college or work placement (but not university)
- Parents can start the process if the education setting is not willing to do so, and all professionals involved with the child will then be asked to provide information by the local authority.
- YOUR CHILD DOES NOT HAVE TO HAVE A DIAGNOSIS all you have to show is that your child has
 additional needs around education which would benefit from greater support than they are
 currently receiving.
- A decision should be made about whether the LA is going to proceed with a needs assessment within 6 weeks and the whole process should take 20 weeks but often takes longer.
- If, after 6 weeks, the LA rejects the application, APPEAL. A high percentage are accepted on appeal.
- You will receive a draft plan which you can make changes to. A good plan should be easy to read and understand, not overlong, specific so that it is enforcable so not 'speech & language therapy would be beneficial' but '2 x 30 min sessions of S & L interventions per week, delivered by a trained TA and following a programme provided by a S & L Therapist'.
- You can ask your EHCP co-ordinator to name a specific school in the plan which *should* then allow your child to access that school. The LA has to notify the school that it is to be named in an EHCP and there are some legal reasons why they can refuse to do this.
- For specialist support and advice go to:
 Independent Provider of Special Education Advice IPSEA
 Norfolk SEND Partnership SENDIASS
 Norfolk's Local Offer website https://www.norfolk.gov.uk/children-and-families/send-local-offer
- BREAKING NEWS Norfolk County Council has a brand new Helpline for EHCPs EHCP county contact number: 01603 679183
 The phone line is open:

9am-5pm Monday - Thursday 9am-4pm on Fridays



Norfolk and Waveney ASD/ADHD Support Service has teams working across Norfolk and Waveney to provide support and advice to families just like you.

What can you access in February?

Every Tuesday from 10:30 to 11:30am you can join one of our **Zoom Support Sessions**. Try it out. You will meet other families who understand the issues and at least one of our team to answer questions. You just need Zoom and the following details to get started.

Meeting

ID - 928 5803 9218 and Password - 286707

We also offer monthly **Information Sessions** on **Zoom**. In February, the topic will be....

Understanding Meltdowns and How You can Help

Wednesday 24th February 2021- 10 to 11am

Meeting ID: 979 1677 1548 Passcode: 820021

Remember that our very popular **Positive Behaviour Strategies course** has been made available as six short videos which you can access from the comfort of your own home. Each video is arround 15 to 20 minutes in length and they cover Understanding your Child's Needs, How Needs Translate to Behaviour, Planning for Better Behaviour, Communicating Better with Your Child, Strategies to Try at Home and Dealing with Meltdowns. You can find these on the NHS website, Just One Norfolk, or by clicking on https://www.justonenorfolk.nhs.uk/childhood-development-additional-needs/behaviour-sleep/positive-behaviour-support-pbs It would be great if you watch a video, to please click on the feedback link as this helps us to keep improving the service we provide.

If you wish to join our closed **Facebook** group, go to Facebook and to the Family Action page and then search for Norfolk and Waveney ASD and ADHD Support Service.



....is a free service available to support adult family members on all aspects of family life issues via telephone, text message and email. Whether it's emotional support or practical advice on any aspect of parenting or broader family issues, call: 0808 802 6666, text: 07537 404282 or email: familyline@family-

action.org.uk

Monday to Friday: 9am – 3pm and 6pm – 9pm. The helplines will be covered by SHOUT our text crisis line outside these hours including weekends and bank holidays.

To contact us for advice and support:

Phone Swaffham 01760 725801/720302 or Email Swaffham@family-action.org.uk
Phone Gorleston 01493 650220 or Email Gorleston@family-action.org.uk
For North and South Norfolk and Norwich please ring Swaffham or Email Central@family-action.org.uk
Unsure which area to contact? Use any of the above – We are all here to help you.