

Some children struggle with behaviour that can be challenging. Yvonne Newbold is a professional on Violent and Challenging/Controlling Behaviour (VCB). She runs webinars, courses, Facebook groups, and training. If you are experiencing VCB from your ND child or adult, I highly recommend joining her groups and partaking in her courses and training.

She has a website which can be found at: <a href="https://www.yvonnenewbold.com">www.yvonnenewbold.com</a> The following is a guide that she wrote for parents.

# BASIC INFORMATION FOR PARENTS

If your family is coping with ongoing violence and challenging behaviour from a child with a neurodevelopmental disorder, here's some basic information as a guide only. I've written it from a parent's perspective, drawing from what I learnt during the ten years that my son, Toby, presented with behaviours which were both violent and challenging. I know that there is always hope because Toby successfully turned his behaviour completely around, and his future looks much more optimistic than I once ever dared hope for. It took a long time and a lot of hard work, but we got there, and I am so proud of him. If Toby can do it, so can your child. This could be where you start from...

#### 1

When a child has a neurodevelopmental condition, violent and challenging behaviour is very common. Around one in four of all children with a diagnosis of autism or a learning disability, will develop behaviour which is both violent and challenging, also called VCB. Children with other conditions such as ADHD and PDA can also present with these behaviours. (See IAN Community Scientific Liaison Kennedy Krieger Institute)

#### 2.

VCB in these children is not caused by poor parenting, this is not your fault. Nor is it your child's fault. It is part and parcel of having a neurodevelopmental condition. However, with the right intervention and support, a child can turn their behaviours around completely.

#### 3.

VCB can present in many different ways. It can be physical attacks on parents, siblings and others that may include lashing, punching, kicking, hitting, hair-pulling, biting, throwing things, using household items as weapons or missiles, intimidatory behaviour or language, insults and other verbal attacks. It also includes destruction of property and of the home.

# 4.

Although it looks like extremely bad behaviour, it is not. VCB stems from a place of extreme anxiety and can be triggered by a number of issues such as sensory processing differences, transition difficulties, school issues, communication difficulties and many others.

# 5.

All behaviour is a form of communication. VCB is no different. Behaviours also often have a purpose. When a child behaves in this way, they are often trying to tell us something, and they are also possibly meeting one of their own needs. Working out exactly what they are trying to tell us and why they are doing it will help us understand our child and their behaviours better, and that is often the key to starting to work out how to turn VCB around. However, it's not easy to work out what's behind their behaviours, and the reasons are seldom obvious or easy to detect.

#### 6

Yes, this behaviour can be turned around. Children can be supported to develop more effective and less dangerous ways of communicating, as well as strategies that can help them get their needs met. Never give up hope.

- 7. However, there are few, if any, overnight "quick fixes". Progress will be measured in tiny steps, and there are likely to be periods of time when families feel they are getting nowhere or even going backwards. Hang on in there and keep going.
- 8. When children are in the middle of a violent meltdown, it means that they are in the middle of huge and overwhelming distress. Their "fight or flight" mechanism has kicked in, and they are literally either fighting or, in some cases attempting to run away because they feel their very survival is at risk.
- 9. The "fight or flight" mechanism is a perfectly normal response to fear, stress and anxiety. It evolved to save our lives thousands of years ago when the most likely cause of fear, stress and anxiety was to come face to face with an enemy or predator and to stay alive, we either had to fight our way out of trouble, i.e. killing the predator to stop it killing us, or to run away faster than it could keep up. Although society has changed so that 21st-century causes of fear, stress and anxiety rarely need such a physical response, the human body in all of us is still wired to react this way when we feel under pressure.
- 10. When the fight or flight mechanism is triggered, all our energies are focused on our muscular strength, and our brain partially shuts down to enable us to sort out the situation physically. This means that a child who is in the middle of a violent meltdown will have limited access to the part of their brain that makes judgements, controls impulses, listens to reason, or responds to requests.
- In this heightened emotional state, a child is extremely frightened, very confused and unable to process thoughts or ideas clearly. If they hear a parent shouting at them, or if they pick up panic, tension or judgement in someone else's voice, their own sense of being in danger may increase, and this can escalate the violent meltdown. At this stage, the child has lost self-control completely and cannot respond rationally to other people. Any verbal instructions, requests or displays of emotion from others will only confuse them further and may make things worse.
- This means that, in the middle of a VCB episode, it is essential to stay as calm, as quiet and as non-threatening as possible. Now is not the time to get cross with them, tell them off or even to show your own emotions if at all possible. This is very hard because a child in the middle of a violent meltdown will have a detrimental emotional effect on everyone in the vicinity, particularly family members. It takes lots of practice and effort to remain calm and to maintain a neutral tone of voice, but it is probably the one single most important thing to do in the middle of an extreme meltdown. To be able to stay calm, it helps if you can boost your own resources and resilience and to be aware of the importance of your own mental wellbeing. That's why I've also written 15 Resilience Tips for Parents of SEND Children with VCB.
- A child in a meltdown is already completely out of control and frightened. You, their parent, are their rock and their safety net. If you can convey to them a sense of calm, rock-solid security, they will feel reassured and less frightened. However, if they see you not coping well because they are having a meltdown, and they can sense a tone of panic or fear in your voice, their fears may intensify. They are likely to follow your emotional lead, and if you are showing fear in your body language, voice and actions, this may feel to them as if you are confirming that the world is actually a very unsettled and unsafe place right now, and it can make the meltdown worse and last longer. I know it's a big ask to pretend that all is calm and happy with the world while you may be being physically attacked, but a calm voice, in particular, can really help de-escalate the situation.

One method of keeping emotion out of your voice is to sing whatever you want to say. Singing keeps our voices neutral and without negative emotions such as anger, fear and judgement almost automatically. Just sing words to a tune that let your child know that you are there, you understand, and that things will be OK. Keep it very simple, clear and positive. Also, give your child lots of time to process those words before repeating them or saying something else.

## 15.

Try to discourage other people from talking at all within the child's earshot during a meltdown. Right now, your child is out of control, past overload and completely overwhelmed. Competing voices in the same room are likely to be counter-productive.

#### 16.

Give the child time and space as much as possible. Trying to restrain them may increase their sense of fear and panic and make things worse. However, safety is of paramount importance always – the child's, your own, their siblings and anyone else in the vicinity. If possible, move other people as quickly as possible to a place of safety – another room in the house, for example, until the meltdown has run its course.

#### 17

The most common causes of meltdowns are extreme anxiety which can be triggered by a number of things, including sensory overload. Many neurodevelopmental conditions cause sensory processing issues, so that sounds, smells, lights, touch, etc., may cause difficult and sometimes painful sensations in a child, which can build up until they are unable to cope. If you can work out which sensory issues are most likely to cause your child difficulties, there are lots of things you can do to alter their immediate environment to make things easier, which may preempt a lot of difficulties. Ideally, it can be extremely useful for your child to have a thorough Assessment by an Occupational Therapist who has been trained in Sensory Integration. If that isn't possible, your child's behaviour may give you clues as to which aspects of sensory processing they struggle with the most. There are often simple adjustments that can make a huge difference such as noise cancelling headphones or creating a safe space for a child to retreat to when things begin to get overwhelming.

#### 18.

During a meltdown, due to possible sensory issues, lowering the lighting and reducing noise can make a significant difference too. Try to reduce any sensory stimuli as much as possible, including touch. If a child is upset or distressed, a parent's instinct is often to comfort them with a touch or a hug. However, consider that during a meltdown this may make things worse for some children but not others. Some children may find this sort of touch calming whereas, for others, it can increase their sense of being overwhelmed. Try and work out what your child needs right now from you, and be alert and aware to anything that may be adding to a child's sensory overload, as well as what might reduce it.

#### 19

Other causes of extreme anxiety can be transitions. This is when a child is asked to stop doing one task so that they move on and do something else. It can be as simple as asking them to turn their ipad off because it's teatime. Children with neurodevelopmental disorders often need time to process change, and plenty of warning that one activity will need to stop soon. They can react very badly to being expected to stop something without prior warning. Timers can be helpful so that a child is told that in ten minutes, it will be dinner time, and then they are given a timer so that they can see visually how time is passing.

Visuals can help enormously, both in the middle of a meltdown and in day to day life, to give a child more understanding of how their day is likely to progress. A "Now/Next/Later" board can be particularly successful. Most of us use visual information to augment understanding. For example, when we hear the news on the radio, it often has a lesser impact on us than watching the same news item on TV would have. Our children are the same – use visuals to let them know what is happening next, to help them understand better.

#### 21.

If a child is going to have to stop using their iPad because something else is happening soon, visuals are also a very good way of letting the child know when they are likely to be able to use their iPad again. It can be helpful to create a chain of visuals with "iPad", "dinner", "bath", "iPad" "bedtime". Some of our children have difficulty with finishing tasks because the loss can seem much greater than it really is, and they may not have any idea if they will ever be able to use it again. A visual can help to reassure a child that they will be able to go back to what they want to do later on.

#### 22.

Communication impairments are much more common in children with a neurodevelopmental disorder, and they can also be very difficult for us, as adults, to recognise. A child may have a very large vocabulary and may be able to express themselves well but may not be able to process and understand what is said to them to the same level of competence. Yet, adults may assume that the child has understood everything perfectly. Communication impairments can also be a huge cause of anxiety, causing frustration if a child is unable to clearly articulate how they are feeling and what they need right now. When a child starts to become distressed, their communication skills can become even more significantly impaired. When adults don't recognise this, a child's communication difficulties can go unnoticed, and this can cause assumptions and misunderstandings to occur, which can compound each other, and things just get worse. Visuals can augment understanding with even the most fluently spoken of children and may help to reduce anxiety too. It can be helpful to assume that a child will be finding certain aspects of communication difficult and have visuals to help on hand anyway.

#### 23.

School can be a source of anxiety for a child, and a very common pattern that many parents see is that the child comes home and explodes into a violent meltdown very quickly. Many people can draw the wrong conclusions and assume that the child is happy at school because they behaved well all day, but that there must be something horribly amiss at home if that's where the behaviours are happening. In fact, the complete reverse is true. Home is where a child feels safe and secure enough to let all their emotions out, so they will hold onto all their negative feelings and bottle everything up until they get home where nobody, except family, can see it. If this sounds like your child, it may be that they are "masking" their difficulties during the school day and at other times too. Masking is a well-documented coping mechanism that many children use to hide their anxieties and inner turmoil; you can google it to find out more.

#### 24.

A child will often seem to deliberately target their primary caregiver, often their mother. Not only is this incredibly hurtful and difficult for a mother to cope with, others may make an assumption that this proves that the mother is the one who is somehow causing the child's behaviour. Nothing could be further from the truth. It's because a child trusts the person closest to them the most that they also get the worst of their behaviours.

#### 25.

Since VCB is not caused by disobedience or unruly behaviour, the standard tried and tested behaviour strategies used by parents everywhere simply will not work. This is fundamentally a child crying out for help in extreme distress, so they need help and support rather than being asked to sit on the naughty step or not being allowed an ice cream. This is not caused by parents not being strict enough or a parent who is "too soft" on their children. This is much deeper and much more complex, with the child needing an empathetic approach rather than judgement.



If your child is presenting with VCB, it's great if you can get appropriate and highly skilled help and support as quickly as you can. However, the reality is that demand so far outstrips supply that there simply aren't enough trained professionals to work with every family who is facing this. Most families never get any specialist help and are on their own to sort things out the best they can. What can really help is to start a journal where you record every incident of difficult behaviour. Jotting down a record of what happens, the time, how the day had been immediately beforehand, and anything else relevant can be helpful for you too since you can soon see if there are any patterns emerging that you might not otherwise have noticed, as well as if the behaviours are worsening or getting better in some way.

# 27.

You may have to be your child's behaviour detective. Every time they have a violent meltdown, regard it as an opportunity to gather potential clues for what is underlying their behaviours. Write any thoughts down, too – sometimes patterns and themes emerge over a period of just a few weeks which can give you some indication of how to help your child.

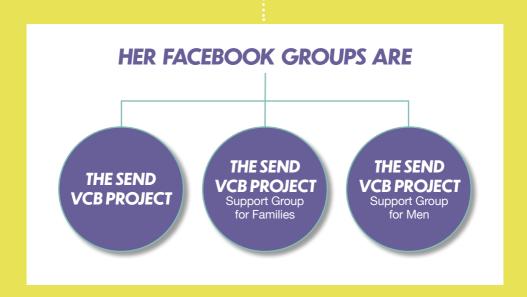
### 28.

You cannot change your child's behaviour by telling them to do so. None of us can enforce change on anyone else; it generally has to come from within. However, you can change how you do things and how you think about things relating to VCB, and that may mean your child responds completely differently to your new way of doing things or how you think so that they do change their own behaviours too. When this was first pointed out to me. I found it hard to accept because I felt I was being blamed all over again for Toby's behaviour and that I was being told that it was all my fault because I was doing it wrong. Eventually, I came to see that this wasn't the case at all but that the only way to change Toby's behaviour was if I changed my behaviour first. The thing is that if we continue to do things the same way we've always done them and they haven't worked, we will get exactly the same unwanted results again and again by doing things in the same way. Try different approaches, perhaps step back instead of approaching a child in mid-meltdown, or see if it makes a difference being completely silent. Distraction can work, too, so you could try doing something completely unexpected or different. Experiment with different ways of doing things, not just when a meltdown is happening but at other times too, and you may see different and maybe more positive responses in your child as a result.

Never stop believing in your child, and never give up hope that you can help them find their way through this until they can move on towards a much more optimistic future where they are able to express their fears, anxieties, stresses, frustrations and needs in a much more positive way. Look for their passions and try and find the joy within your child. Look for the positives and celebrate them – they will be there, but sometimes the behaviours can make them harder to find. Read everything you can about sensory processing issues, find out about using visuals to aid communication, and also try to see and experience the world from your child's point of view. Think of yourself as their team-mate and advocate when they have a violent meltdown – they need your support, and they also need your help in finding better and more productive ways to ask for it.

#### 30.

Never stop believing in yourself too. When you have a child with this sort of behaviour, we often blame ourselves, we feel others judge us, and we also feel ashamed that we are unable to prevent their meltdowns. This is not your fault; you are doing an amazing job, you are stronger and more resilient than you think, and you will get through this. Please also know that you are not alone – there are thousands of families everywhere in the same situation. Talk about it to people you trust, try and find other families who are facing the same difficulties, either online or in real life. It's so much harder doing this on your own, so if you can get some practical help from friends and family, see if you can build a small support team around you and your child. Look after you too, treat yourself, take some quiet "me" time whenever you can, even if it's only for a few minutes every day, and find some way to recharge your batteries and to help you keep going.



Essex Partnership University Trust provides The Children's Learning Disability Service (CLDS). This multi-professional healthcare team assesses and treats children with moderate to severe learning disabilities who exhibit challenging to manage behaviours. The team are comprised of registered LD Nurses and Sensory Integration trained Occupational Therapists alongside support staff.

The service aims to identify the function of a child's difficult to manage behaviour, including any sensory processing problems impacting their behaviour, and use this to inform a Behaviour Management Plan to help modify the behaviour and improve the child's overall wellbeing and level of functioning.

The team offers individual assessments, parenting groups and workshops, and direct intervention with children individually and group-based intervention. Services offered include functional behaviour assessments, sensory processing assessments (or a blend of both), community-based sleep assessments, health and sexuality assessments and treatment and emotional wellbeing support (including anger management, mindfulness and meditation and yoga).

# The Service provides useful guides on their webpage which can be found via the following link:

www.eput.nhs.uk/our-services/essex/essex-learning-disability-services/childrens-adolescents/childrens-learning-disability-service/

# Another helpful website providing information and support about children with challenging behaviour is:

www.challengingbehaviour.org.uk/

