The question that many parents ask is: how do I know what are neurodevelopmental challenges for my child such as impulsivity or hyperactivity, which is common in children with Tourette Syndrome (TS); and what is simply naughty or oppositional behaviour? The answer is that it can be very difficult to know. However, as a general rule ‘planned’ mischief that is premeditated is not due to these neurodevelopmental challenges.

All children can be naughty, defiant, aggressive, impulsive or rude. The behavioural problems seen in children with TS are usually impulsive and occur in the spur of the moment although they usually have a fairly predictable pattern.

A child with TS and associated neurodevelopmental conditions may show more oppositional behaviour than a child without neurodevelopmental difficulties. The child will therefore need more help in learning to control their emotions; very clear and predictable rules and standards for acceptable behaviour and behavioural management, that is learning which behaviours are appropriate in which situation.

The message given to parents to ‘ignore tics’ should not be mistaken for ‘ignore unacceptable behaviour’. Although the parameters of parenting may alter slightly for children with TS, it is vital that inappropriate and unacceptable behaviour is managed effectively by parents.

Preparation helps to plan ahead and prevent behavioural problems from starting, or at least have in place effective strategies if they do start. We are suggesting in many ways, that you have to have finely tuned, well planned out parenting skills that would not be required in parenting a child without neurodevelopmental challenges.

We recommend the following strategies:

1. Make extra time to leave early, wherever it is you are going to. Accept that this is one of the necessary tools in supporting a child who may struggle with being organised and aware of time management. This way you will not be as emotionally upset with your child as you would have been if you had not prepared yourself and them to be ready.

2. If your child is going out with other children, talk to the supervising adult beforehand. Explain that your child may have difficulties and it would be helpful if someone can look out for early signs of excitable behaviour. Agree with the supervising adult what action should be taken to calm the situation down if your child starts to show these signs.

Examples:

- If going to the cinema or theatre, choose aisle seats that enable you to make a quick exit if behaviour gets out of hand.
- If going to a place where you have to wait for a long period of time, such as a restaurant or airport, make sure you have plenty of activities to distract your child. This could include books, drawing materials and pocket computer games.
- If eating out as a family, think about seating arrangements. It may be better to sit in between your children to stop them fighting and causing a scene. Choose restaurants that serve food quickly or have a buffet service.
- Go to shopping malls when they are less crowded and there is less stimulation
- Be prepared for comments from other members of the public and think about how you might respond if they approach you. Practising your response beforehand can make responding to someone less upsetting for you.
Behavioural management

The basic rule is that most children want some sort of attention as they may struggle to think about how to entertain themselves alone for long periods of time. This is particularly pertinent to children with TS and Attention Deficit Hyperactivity Disorder (ADHD). If children do not get positive attention regularly, they will do whatever they can to gain this attention. This may be negative behaviour such as shouting, teasing siblings, breaking objects. The more exhausting and challenging the behaviour of the child is, the more likely that he will receive negative and critical comments from parents and teachers, so it is worth noting that constant negative feedback will encourage negative attention seeking.

If possible, praise positive behaviour (e.g. when your child is playing calmly with their siblings) and ignore attention-seeking behaviour, even if they are somewhat noisy (e.g. flicking through TV channels), unless it is dangerous or violent. It is important to choose your battles.

If limits and boundaries are broken you can try out the strategies that are mentioned below. Please note that the strategies suggested are general evidence-based parenting approaches. There are many factors that might determine how well a child responds to a particular approach – there is no one size fits all solution.

CASE STUDY

Kate’s 9 year old daughter Suzy has TS and OCD. Kate finds that if there are any upcoming changes to Suzy’s routine, like day trips, holidays or sleepovers, preparing her for them can help reduce stress levels and prevent behavioural issues arising. Suzy has a calendar in her bedroom which Kate writes upcoming events on, and Suzy has a chalkboard where she scribbles notes to herself. Suzy also has a notebook by the side of her bed so she can write down her thoughts and leave notes around the house. Kate makes a point of regularly discussing upcoming events with Suzy a couple of days before. They discuss the details of the events, including how the transport will be organised, who will attend and what might happen on the day. Importantly, they also discuss what might happen if the predicted events do not happen the way that they have discussed. It takes time but it is certainly worth it.

Getting your child to do what you want

If carrying out a particular behaviour leads to some sort of reward (positive or negative attention) then it is more likely that the child will carry out the same behaviour again. If there is acceptable behaviour and it is not rewarded with praise, then it is likely that the behaviour will diminish. Therefore, if you want good behaviour to continue, you must keep praising and rewarding it in some small way. This can be use of encouraging words, pats on the back, hugs or simply saying ‘I’m really proud of you’. It is a good idea to vary the praise so that the child does not get bored. As children with TS and associated behavioural challenges may be more demanding and exhausting than their peers or siblings, parents may find it hard to notice the good behaviour and overly focus on the negative actions.

Keep a close eye on good behaviour and remember to reward it with praise if you want it to continue. If there is unacceptable behaviour and you reward it with more attention than a simple verbal ‘no’ – maybe getting annoyed and screaming at your child – then it is likely that the behaviour will continue. If there is unacceptable behaviour and no reward then it is likely that the unacceptable behaviour will diminish.

Praising your child and setting limits

When you notice your child engaging in positive behaviour, praise the behaviour immediately. This will lead to the acceptable behaviour being more likely to occur. Be specific about the praise and label the behaviour that you are praising so the child clearly understands. Children with TS may benefit more from praise than children without neurodevelopmental challenges.

Set firm boundaries and limits

The child with TS and ADHD will really test your limits and boundaries to the full. When setting limits and giving instructions:

- Be brief but clear.
- Don’t shout or lose control yourself – know your own limits.
- Specify the desired behaviour you want.
- Avoid trivial rules and commands. Don’t have rules about flicking channels on the remote control for the TV but do have rules about hitting siblings. Agree with your partner on a limited number of house rules – five or ten, not hundreds.
• Use when-then commands: when you have tidied your bed then you can play.
• Praise good behaviour, e.g. ‘I really like it when you share with your sister’.
• Make sure there are consequences for not following instructions, e.g. ‘If you do not stop using the computer in five minutes at 6pm then you will not be able to use it tomorrow’.
• Be consistent.
• Talk to your child about their behaviour when everyone is calm. Help them to understand what rule was broken.

Using clear instructions

Ultimately children want praise and to please you. They are therefore more likely to follow instructions that are said in a positive than a negative way. For example, if a child walks on the carpet in muddy shoes and you say, ‘Don’t walk on the carpet with muddy shoes,’ the likelihood is that he will do the same next time. If you were to reframe the command and instead say, ‘It was great when last time you took off your muddy boots before walking on the carpet,’ then a child is more likely to respond to this and remove their shoes next time. Make sure your child can see your face when you give instructions. If your child is not paying attention, ensure your child can look straight into your eyes and be firm with your command. It is OK to look serious but avoid shouting, being physical with your child or using threats. It is very important not to say that you will not punish your child and then change your promise.

More serious behaviours and how to respond when limits are broken

The following strategies are drawn from various different models of parenting which have emerged in the past decades and found to be effective for primary school aged children. Children respond and parents are able to implement different approaches, often depending on their own temperament and beliefs. It may be important to read a book, watch an educational video or attend a course which can show you more about these approaches:

Nurturing self-regulation to your child

Talking to your child about their emotions and how these develop can be helpful. It’s important to know that your child knows that their emotions are an important aspect of them and that with practice and insight they can gain greater control of their feelings and ultimately, their reactions. An insight into how their brain works with emotions is very helpful, particularly when the brain-related information is presented in an understandable way for them. An understanding of the primitive and more developed parts of the brain can support their role in managing their behaviours. This process requires practice both for parent and child but hopefully will result in a teenager who can understand and ultimately manage their feelings in an adaptive way. Many parents report that when they start to talk with their child about their feelings, they develop their own ability to manage difficult emotions.

If limits are broken then try using time-out, as described below:

Time-out

Time-out should be used for serious behaviour only, such as fighting, rudeness to you or destructive and aggressive behaviour. Time-out involves sending or taking your child to another room where he can calm down. Agree on a safe room to calm down in. Don’t use the kitchen or garage where there will be sharp implements and tools. Bedrooms are good to use as time-out rooms. It doesn’t matter if they are able to play in their room. Time-out is not a punishment – it is time-out from your attention! You can think of it as a positive way to calm down. The rule is a minute for the age of the child, so if he is eight years old he has time-out for eight minutes. Unless he is extremely violent, it is important to ignore him while in time-out. He may throw things about and make a mess. If he does make a mess, make sure he is responsible for it and either tidies it up or carries out a chore to pay for any damage. Combine this with other techniques such as loss of privileges and treats.
Response – cost
Response cost is the removal of privileges from the child when they break rules. To avoid seeming as if you are endlessly penalising your children, counteract this with enjoying play-time with your child, use of praise for good behaviour and plenty of affection. If your child has done something such as stolen sweets from a shop, make him go to the shop to apologise and pay for them. If he has damaged the neighbour’s fence, then he should be made to repair it or at least do chores to pay for it. This way your child will see that he has to be responsible for his actions. In the example of Sally, the parent re-enforces the message that there are consequences to actions, without penalising her daughter for her condition. Another example of response-cost could be enforcing a period of no computer games/TV.

Look after yourself
We tend to lose our temper, be irritable and enjoy interactions less with our family when stressors have been building up, or when we are tired or hungry. Therefore remember to look after yourself and your health. Remember to make time for yourself, this could be finding time to go for a walk, have a chat with a friend or get your hair cut. Exercise can be a good source of stress relief but also problem-solving with a partner or close friend. This way you will be in a better frame of mind when dealing with your child.

More information
The information in this factsheet is based on that available in the book, Tic Disorders: A Guide for Parents and Professionals (2017) by Uttom Chowdhury and Tara Murphy.

Recommended reading
The Incredible Years by Carolyn Webster Stratton:

No-Drama Discipline: the whole-brain way to calm the chaos and nurture your child’s developing mind (Mindful Parenting) by Dan Siegel and Tina Payne. Scribe UK:

CASE STUDY
12 year old Sally occasionally has rage attacks. On one occurrence, Sally threw her phone across the room and smashed the screen. After the rage attack passed Sally’s mum suggested to Sally that when a rage attack happens again, and she feels the urge to throw her phone or any other breakable item, to try to throw it at her beanbag, or her bed. Sally’s mum agreed to get the phone screen fixed this time but said that if this happened again, Sally would have to wait longer until the screen got fixed.

Not reinforcing negative behaviour
Often it is not easy, but try not to lose your temper and try to stay calm. Try to keep a neutral face and lower the volume and pitch of your own voice. You are a role model for your child so show them and teach them to be the way you want them to behaviour through your own behaviour.