# Tourettes<sup>2</sup> action

# Behaviour problems and Tourette Syndrome



## Coping with behavioural problems

The question that many parents ask is: how do you know what is Tourette Syndrome (TS) and what is simply naughty 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 TS. The behavioural problems in TS are usually impulsive and not planned.

All children can be naughty, defiant, aggressive, impulsive and rude. A child with TS and associated behavioural difficulties will show a lot more oppositional behaviour than an average child and will therefore need more help in terms of discipline (rules and standards for acceptable behaviour) and behavioural management (learning appropriate behaviours).

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

## Preparation

It helps to plan ahead and prevent behavioural problems from starting, or at least have in place effective strategies if they do start.

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. Wherever you go be prepared to leave early. Accept that this is one of the drawbacks of having a child who is more boisterous than most children. This way you will not be as emotionally upset with your child as you would have been if you had not prepared yourself.

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.

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#### **Behavioural management**

The basic rule is that most children want some sort of attention. This is particularly pertinent to those children with TS and associated Attention Deficit Hyperactivity Disorder (ADHD). If children do not get positive attention regularly, they will seek out negative attention, whatever that may be, and do their very best to get it.

The more exhausting and challenging 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. (See praising your child and setting limits).

If possible, ignore attention-seeking behaviour (unless it is dangerous or violent). If limits and boundaries are broken use strategies that are mentioned below:

#### 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 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 will be more demanding and exhausting than most, parents will find it hard to see the good behaviour, and the 'naughty' behaviour dominates everyday life.



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 being good, praise this 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. The typical child with TS will need more praise than others.

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
- Specify the desired behaviour you want
- Avoid trivial rules and commands. Don't have rules about flicking channels on the remote. Do have rules about hitting. Agree with your partner on certain house rules – five or ten, not hundreds.
- Use when-then commands: when you have tidied your bed then you can play
- Praise good behaviour
- Make sure there are consequences for not following instructions
- Be consistent

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 would be really good if you took off your muddy shoes before walking on the carpet', then a child is more likely to respond to this and take off his shoes next time.

Make sure your child can see your face when you give instructions. If your child is not paying attention, hold him by the shoulders, look straight into his eyes and be firm with your command. It is OK to look cross but avoid shouting.



#### When limits are broken

If limits are broken then try using time out, response-cost or the 1-2-3 response to back chat. See below:

#### Time out

Time out should be used for serious things only, such as fighting, rudeness to you or destructive and violent behaviour. This 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

This is the removal of privileges or payment of a fine.

To avoid seeming as if you are endlessly penalising your children, counteract this with positive praise for good behaviour.

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.

12 year old Sally occasionally has rage attacks. On one occurrence, Sally threw her ipod 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 ipod or any other breakable item, to try to throw it at her beanbag or her bed. Sally's mum agreed to get the ipod fixed this time and said that if this happened again, Sally would have to wait longer until the ipod got fixed. 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.

## **Back chat and endless arguments**

Many parents often feel exhausted by the constant back arguing, 'back chat' and debate they receive from their children. Once you tell a child off, he will talk back and debate the issue endlessly.

Dr Thomas Phelan, author of 1-2-3 Magic: Effective Discipline for Children 2-12, provides effective strategies to help deal with stopping particular behaviours. He suggests using visual cues of raising a finger to indicate 'one' as a warning if your child has over-stepped the boundaries. If he persists again, which he usually will, then raise two fingers to indicate 'two'. If he still persists then raise three fingers to indicate 'three'.

The parent should not speak at all during this, apart from saying 'one, two, three' when raising his/her respective fingers. By doing this, the parent avoids getting drawn into the time consuming debate which the child usually wins. With continued use of this method, the child is likely to stop a particular behaviour by the time you get to the first or second stage.

If the child does not stop their behaviour you can use the cost-response and/or time out strategy.

## Looking after yourself

Often it is not easy, but if at all possible 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. We tend to lose our temper when things have been building up, when we are not relaxed, when we are tired, hungry and stressed.

Therefore remember to look after yourself and your health. 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, Uttom Chowdhury and Tara Murphy* (2017).