

Understanding Tourette's



Tara Murphy and Fiona McFarlane explain how Tourette's affects children, how to live with it and what the treatments are

What is Tourette's syndrome?

Tourette's syndrome is a common neurological condition affecting up to about one per cent of children. Children with Tourette's experience both vocal (sound) and motor (movement) tics and frequently have difficulties with other areas of wellbeing and learning.

At our specialist tic disorder clinic at Great Ormond Street Hospital we see many children with Tourette's. Sometimes, parents are very concerned about tics (involuntary movements and sounds that occur singly or in clusters for a long period of time called tic attacks) and can focus less on the rest of their child's life. As motor and vocal tics are very noticeable it can make parents, teachers and professionals very concerned that the tics could cause the child to be targets for bullying or impair their quality of life. This is rarely the case. To explore these issues, this article will describe the experience one child with Tourette's and his family as they learned more about Tourette's and how to live with it.

Peter, an eight-year-old, recently attended our clinic with his parents. Peter has had involuntary motor movements and vocalisations for about two years. We discussed how the movements and sounds are called tics. The first tic Peter had was a rapid eye blinking, which is a very common tic. He then started to open his mouth, jerk his head and shrug his shoulder. As the head jerk reduced in frequency Peter then developed a sniffing vocal tic which persisted. He then started to clear his throat and a very quiet squeak emerged, which was most noticeable when he watched TV. Peter's parents were worried and went to see their GP who suggested that Peter would probably grow out of the tics and not to worry. This was good advice as tics are common in primary school children and many children grow out of them. But when the tics changed and new tics appeared Peter's parents continued to worry and asked to see a paediatrician. Peter's father and grandfather had both had tics when they were younger and grandfather still sniffs most days, although it doesn't bother him.

Peter himself was not worried about the tics. He was in Year 3 at school and no-one had ever mentioned the tics to him. At times he noticed a head jerk when he was reading but the movements and sounds had not bothered him. He didn't know what to call the tics, though, and was aware that his parents sometimes worried about him.

The paediatrician told Peter that he had Tourette's syndrome and referred him through to our clinic. Peter and his parents came to the clinic with lots of questions. Their main concern was how to help Peter stop his tics as they were worried that he could be bullied or misunderstood by people. They described worries about what might happen with Peter's tics and what could happen in the future. Their toolbox for managing Tourette's was quite empty. We discussed the sorts of treatments that have helped other children. We divided the treatments into several categories.

Becoming an expert on tics

The first and most important treatment was learning about Tourette's and becoming an expert on tics. Peter learnt that Tourette's syndrome is a neurological condition which is often passed down in families. He understood that for most people with Tourette's, tics start at about six to seven years of age with motor tics. Then, about one to two years later,

children with Tourette's typically develop vocal tics. The tics wax and wane, with days with lots of tics and other days with few tics. The tics typically tend to be at their most frequent between ten to 13 years of age. From about 14 years of age, most children's tics start to reduce. Peter learnt that many people either grow out of their tics or the movements and sounds become so unimportant in their lives that they don't then notice when they have them. We also explained to Peter that it might be helpful for him to tell some of his friends about having tics. We explained that doing a presentation for classmates about Tourette's can be helpful. We showed Peter and his parents an example of a presentation available on the Tourette's Action website and told them about research which said that this was a good idea.

Peter himself reported that he was not sure what he might say if someone asked him why he had made a noise many times or why he blinked so much. He wasn't sure how he might explain the tics to the person. We discussed how this would be an important activity for Peter to practice with people he knew well, in the beginning, before telling people he knew less well. This would mean that should Peter be in a situation where someone he didn't know asked him, he could explain that he has Tourette's, give the person some helpful background information and then distract them with a question about something different.

We recommended that Peter met with other children with Tourette's and that his parents also met with other families to hear about Tourette's syndrome. We invited him to afternoons we run where families could learn and share ideas about how to cope with tics and other difficulties that go with them. We knew from studies that such groups can help children with tics feel happier about their lives and cope better with their difficulties.

Therapies for tics

We discussed that Peter's tics were not really bad enough for him to take medication as they were not bothering him or causing pain. If his tics got worse in the future, we said there were a number of medicines that could be tried. Medicines can't cure Tourette's but they can reduce the number of tics children have. Like all medicines, they can have side-effects, though, so they are only given when tics are really interfering with life.

Peter's parents wondered about psychological therapies to help Peter manage his tics. We explained there are two forms of behavioural therapy which have been shown during the last 40 years to help some people in controlling their tics. Like medicines the treatments are not a cure but they can reduce tics by on average about a third (which is the same as the effect of medicines).

Habit reversal training

This type of behavioural treatment involves the child becoming aware of when the tic is about to happen and doing an action that makes it impossible to do the tic and holding it until the urge to tic has passed. This can happen because many children with tics experience an urge or tension just before the tic occurs which we call a "tic signal". Peter was surprised to know that we had heard about this sensation as he thought he was the only person with this tingling feeling. Sometimes, it didn't feel comfortable to have the tic signal and he was relieved when he did the tic as it meant this feeling went away. During practice time it's the parent's job to notice when the child is doing their tic or alternative action and say how helpful it is. We discussed about how the treatment is not a cure but people with tics can use the strategy in places where their tics are bothersome (such as for vocal tics at the cinema).

Exposure and response prevention

This is a similar approach in which children gain control over their tics by practising suppressing their tics for a short period of time. Children don't have to figure out any actions to prevent their tics but instead try to "hold them in" for as long as possible and to set records for their maximum record time. In doing this they get used to the uncomfortable sensation of the tic signal and discover that it goes away with time even if they don't tic.

For both treatments the child meets with a therapist six to 12 times (depending on the tic severity) to learn the strategy. Importantly, the child would have to spend time practising the exercise between meetings. Peter's father queried if tic treatments were only for children with severe tics. We discussed how this was not necessarily the case but that the main reason to come for treatment was because of the extent to which tics were affecting the child's life. We don't recommend trying these treatments on your own as there is important understanding involved that is best worked through with a professional.

We have also developed a habit reversal training program to treat groups of children at the same time. A recent study we completed showed that the group program helped children control their tics better and also improved how happy they felt about their lives.

Peter told us that, at the moment, the tics didn't bother him and he would rather not miss school or football practice. We agreed that it was a sensible decision not to start treatment at that time; if the tics started to annoy Peter a lot, he could always come back to the clinic.

We discussed how it was likely that if Peter and his family could think about his tics as friends this might be helpful. It was likely that his tics were going to be with him for the next few years. There would be times when the movements or sounds might annoy him, other times when they could be funny and certainly moments when they would be less or more frequent. All the time, though, they would be there in the background, a bit like a friend. We explained that focusing too much on the tics might mean that Peter was less able to focus on all of the other activities he really enjoyed in his life.

Peter will come back for an annual check-up to keep track of how he is doing, in addition to appointments with his local doctor. The family are already much more knowledgeable about Tourette's and thus more able to manage the challenges it throws at them.

Common questions about behavioural therapies for tics

If my child holds their tics in won't they all just burst out later when they stop?

Psychologists have looked at this question very carefully. Studies show that practising holding tics in reduces tics overall. Even if we measure tics just after a child has been holding them in for a while we don't see a "rebound"; if anything, they go down slightly.

If my child stops one tic, won't their other tics just get worse?

The opposite is actually true. When we have looked at this in studies we have discovered that learning to control some tics might actually make all your tics slightly better –even the tics you haven't worked on.

If my child is busy fighting their tics, won't they find it difficult to pay attention to anything else?

When children first learn to control their tics it definitely takes some effort, so perhaps practising in a key lesson or exam might not be the best idea. However, the effect on their attention is small and probably fades as the child gets better at it (just like when we first learn to drive a car we have to use all our concentration but when we get good at it we can think about many other things at the same time).

If my child meets other children with tics, will they catch new tics off them?

It is true that tics are suggestible and children may briefly catch new tics from others with tics. These tic bouts are short-lived however (they usually last only a day or two) and studies show that children who go to groups for children with tics actually experience a reduction in tics overall.

Further information

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Further information about Tourette's is available on these websites:

www.gosh.nhs.uk

www.nhs.uk/conditions/Tourette-syndrome

www.tourettes-action.org.uk