

I am a Parent of a Child with Tourette Syndrome

(This is my story so far)

When Christopher was diagnosed with a tic disorder known as Tourette Syndrome I became very scared and frightened for him and myself. We thought all his health worries were over but this was not the case. Christopher was a very sick little baby for a long time, we nearly lost him at ten weeks of age.

Chris displayed some very strange behaviour around about four, twirling around in the middle of the lounge room floor and running around the house on all fours with his back high up like a baboon. We put it down as a habit like the constant blinking of his eyes. We thought he would grow out of it so we didn't think any more of it.

Starting school was fine however he would always cross the boundaries when it came to playing with kids, especially with his friends. Even though their play was extremely rough to begin with, he seemed to fit in quite well. Chris's second year at school was when the tics became much more pronounced. This is when we really knew there was something going on. His ticcing began to change where it would interrupt his schooling. A new tic had developed in both arms, they would thrust out to the front both at once. It was like you could hear the arms being ripped out of the sockets. It was very frightening to see and soul destroying, I feared for my son.

He started to be aware of some of his tics and at times feared he was going to get into trouble, at other times Chris was totally unaware. School life has been very hard for Chris. He has been branded a trouble maker by the upper school and they have already formed an opinion of him without understanding what is going on with Chris. There have been many times he has been blamed for situations that have occurred.

We were totally unaware of what the implications of having Tourette Syndrome

really meant; the behaviour, the out of control rages, the feeling that everyone is out to get him, even the rudeness that comes with it which gives people a negative impression of Christopher. Even the staff, some definitely formed a dislike of him because they didn't understand that his anti-social and inappropriate behaviour came with the condition. Unfortunately Chris doesn't understand social cues or personal space.

Our home life is very complicated and hard. It has such an impact on the family trying to cope with his aggressive behaviour at times and trying to explain to him over and over, why we have made a certain decision and then to be confronted with what they call a Tourettes repeated aggressive outburst. This can consist of smashing toys, putting holes in the walls or just being plain destructive out of pure frustration because you haven't given him the answer he expected. It is out of his control. It is such a mental and emotional strain on him that he is so exhausted and remorseful afterwards he just falls in a heap.

Not only does Chris have to contend with Tourettes, he also has the co morbidities of Tourettes-ADHD which make it twice as hard for him at school and socially. I feel I have to explain to people all the time so they don't get the wrong impression of him because people are very quick to make judgement. They stare in public because there is no reasoning skills, he hears what we are saying however is not processing or accepting it the way we do so he keeps asking the same question until the answer makes sense to him.

Christopher is an extremely loving and caring boy who would do anything for his friends and even if they don't like him he still tries. He is very good with young children and they seem to be drawn to him. He is very affectionate and

gentle. He recently became a big brother to two guinea pigs which the kids named Violet and Lucy. Chris likes to get in with them.

Christopher has a little sister Kathryn and she is four. He has had to look after her and myself since he was four because I have uncontrolled Epilepsy and couldn't look after her on my own. It must have been a huge strain on him. We thought the responsibility had become too much for him.

At the moment Chris is experiencing multiple tics which consist of both arms swinging out and going over his shoulder, a slight head nod but not as bad as before, a whole body twitch and slight thrust with his body. These motor tics can stop at any time and develop somewhere else on his body. He is also experiencing a vocal tic which at the moment is a popping sound with his mouth. People need to understand that Chris may be able to suppress his tics without knowing it but they come out at home all at once which makes it hard to concentrate and do his homework because of it.

Every child has a right to the best education they can get. Teachers need to understand fully so the class environment can run smoothly for all with as little disruption as possible. The Tourette Syndrome Association can give a talk on Tourette Syndrome, they have first hand experience and it is a free service. Until that is done they are not doing justice to Chris because you can read as much information you want but it won't have the same impact as hearing it from a speaker who knows the ins and outs of the condition and can give examples. Being a speaker for the Epilepsy Foundation in the past I know first hand the value in doing the talks and the fantastic responses and letters I received from establishments and groups of people that I have given talks to.

Anne Wells-Attleir

THE INNOCENCE IN A YOUNG BOY'S EYES.

*A silent cry in a young boy's eyes,
Will they go away,
Never to be seen,
Or will it happen today?
Unknowing what has been.*

*The tic,
The uncontrollable jerk,
The innocence of not knowing
what has been.*

*The anguish of lost friendships,
The lack of understanding,
Will they learn?
Have they been told?*

*The highs and lows,
The happy times and the sad
times.
The growing child's learning to
live with a condition.*

*Anne Wells-Attleir
17/08/06*

