



Tourette syndrome and explaining to other people

Sometimes having Tourette syndrome (TS) can be obvious to people because your tics are noticeable. They might be sounds you make or movements you do. People might notice what you are doing and ask about it. Sometimes, people can make comments without thinking, probably because they do not understand TS. This information sheet gives you a few ideas of how to deal with this situation and what you could say. Think up your own ideas and try them out to see which one makes you feel most comfortable.

Telling people

You might need to start by explaining to people what a tic is and about Tourette syndrome. For instance, Joe who is 14 year old, explains his tics like this:

"Tourette syndrome affects my brain, which makes me have tics. My tics mean I do certain things and make certain sounds. Sometimes the tics change, sometimes they are much more obvious and sometimes you can't see them at all. I can't control the tics for very long and I don't know why I do them. Anyway, my tics are part of me!"

It often helps to explain why you are making sounds or doing movements. You might want to explain that these tics and that most of the time they 'just happen', that you cannot control them. Remember that you are the expert and that other people can benefit from your knowledge. It might help them understand what tics are and help them not to stare or make comments when they next see someone who tics.

Classmates

Your classmates might be a good place to start. They spend a lot of time with you and might have wondered about your tics. You could talk to them about it yourself or perhaps ask the teacher to bring it up, whether you are there or not. Either way, your teacher will appreciate your help in explaining your tics to your classmates.

Have an answer ready

Some young people have found that having a ready-made answer to any questions makes it easier to talk about their tics. You might find it helpful to have your answer written on a card or stored in your mobile phone so you do not have to remember it all. What you say is up to you. Think about what you might say and discuss it with your family. They might have some ideas as well.

Famous people

Lots of famous people had TS and it did not stop them being successful.

- Tim Howard is possibly the most famous living person with TS. He was the goalkeeper for Manchester United and Everton, having started to play football in his native United States. In his first season with Man Utd, he was voted best goalkeeper in the Premiership. He was diagnosed at the age of ten, but refused to let it get in the way of his ambitions. As Tim puts it: 'Never let TS be a stop sign – it's just a speed bump, another obstacle to overcome.' He's also set up a special academy in the US called the New Jersey Center for Tourette Syndrome & Associated Disorders - look at their website at www.njcts.org/teamup.

Further reading

You might find the following books helpful – you can order them from your local library if they don't have them in stock.

Buffolano S (2008)

**Coping with Tourette Syndrome:
A Workbook to Help Kids with Tic
Disorders.**

Instant Help Books. ISBN 1 572 246 324

Peters D (2009)

**Tic Talk: Living with Tourette Syndrome:
A 9-Year-Old Boy's Story in His Own
Words.**

Little Five Star. ISBN 1 589 851 625

Buerhens A (1990)

**Hi I'm Adam: A Child's Book about
Tourette Syndrome.**

Hope Press. ISBN 1 878 267 299

**Nix your tics: eliminate tic symptoms:
a how-to guide for young people** by
Duncan McKinlay is also available from *Life's
a twitch publishing* - [www.lifesatwitch.com/
nixyourtics_book.html](http://www.lifesatwitch.com/nixyourtics_book.html)

Mal Leicester (2013)

**Can I Tell You About Tourette
Syndrome?: A Guide for Friends, Family,
and Professionals**

Jessica Kingsley Publishers

ISBN 1 849 054 07X

so, in short...

- Tell people about your TS and tics if you feel comfortable
- Think about explaining to your classmates or ask your teacher to do it
- Have an answer ready
- Remember having TS didn't stop Tim Howard becoming an extremely successful goalkeeper

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