

Tourette's syndrome should be taken more seriously

January 5 2022, by Melina Malli, Rachel Forrester-Jones



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For many people, Tourette's syndrome is nothing more than blurting out inappropriate words and phrases, including profanities. [Celebrities](#) and even [politicians](#) have used the word Tourette's to relieve the tension of

an awkward situation or excuse their ill-judged outbursts. Many of us have had a giggle or a laugh without giving the condition of Tourette's and the people that are affected by it much thought.

But can jokes and disparaging humor create a climate where stigmatization and discrimination are tolerated and even permitted?

For our [recent study](#) we set out to investigate if people with Tourette's experience stigma and how it may affect their lives. We used an [online survey](#) in which 199 adults in the UK with Tourette's took part, 20 of whom we also interviewed at length.

The participants highlighted how jokes about their condition have, perhaps inadvertently, been used as a weapon against them and contributed to the syndrome not being taken seriously, leaving some unprotected in the face of discrimination. Many of the participants emphasized that they had never been considered eligible for flexible working arrangements despite their disability. Others mentioned that they never received additional time for examinations or extensions for school assignments. One participant, recounting his school days, explained how his parents were summoned to his school: "They [the teachers] said: 'either you take your child out of the school by option and we will keep him on our books and he can do his exams here, or get him out.'"

Our participants also believed that the media, by only focusing on swearing, mocks and oversimplifies the condition. One participant described it thus: "It's like Tourette's is only the f*** word. It's not the pain, not having to open your brain to make the pain go away. Just the swearing. And it's just kind of, 'you have Tourette's, I have Tourette's, everybody has Tourette's' if they swear."

A misunderstood condition

Yet the hallmark of the condition is actually [tics](#) (sudden twitches that cause involuntary body movements) and sounds. The severity of the tics can vary. Some of them may be unnoticeable, but others can be painful and debilitating, making everyday life [difficult](#).

Many people with Tourette's have other conditions, too, such as [attention deficit hyperactivity disorder](#) and [obsessive compulsive disorder](#), which can further affect their [wellbeing](#). Despite these difficulties, our participants said that media depictions and jokes about the condition have contributed to people's perception of Tourette's as a "lesser disability," undeserving of the support that other people with disabilities may be receiving. One participant said: "Of course, they can set me aside, because they don't take Tourette's seriously. They can laugh at us and take the mick and say it's just a joke. Because that's what Tourette's is for them, a joke."

Many participants also believed that mockery and trivialisation of the condition led to inadequate healthcare, including inexperienced GPs who failed to recognize key symptoms of the condition, making the referral process unnecessarily long and complicated. One interviewee recalled having to go to the doctor several times: "They didn't seem like they knew ... they offered me counseling. I had to go back and say: "No, I want to see a specialist." And then I went on the Tourettes Action website, and they gave me a list of specialists. I had to tell the GP exactly who to refer me to. I had to say that quite a few times. He kept saying he couldn't make the referral."

Others discussed the [lack of specialized services](#), including inconsistent advice from their doctor. This inconsistency could be because the UK's National Institute for Health and Care Excellence (Nice) has failed to issue guidelines for treating Tourette's. GPs rely on Nice guidelines to recommend the most appropriate, up-to-date treatment and care for specific conditions. The lack of these guidelines may echo the lack of

attention this condition has received compared with other disabilities, which are taken more seriously.

The [pandemic](#) has highlighted the difficulty of getting help for children with Tourette's—with families feeling neglected by the NHS.

If Tourette's continues to be treated as a joke, the challenges people face in their everyday lives will continue. It's time to take Tourette's seriously.

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Provided by The Conversation

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