

Tourette's Syndrome

My Voice Matters

A Young Healthwatch briefing based on lived experience.

My Voice Matters is ensuring the voice of people with diverse lived experiences and backgrounds are heard.

We are proud to be able to give the opportunity for seldom heard voices to be heard by providers and wider organisations in their own words.

This briefing has been written by Abigail Williams who is studying Health and Social Care at New College and is on placement with Healthwatch Swindon and Bath and North East Somerset (BaNES). It is based on her personal experience and research.

What is Tourette's syndrome?

This is a condition that affects the brain. It involves involuntary movement and sounds which are called tics. It tends to start in childhood but over the years the tics can improve and sometimes they can go completely.

There is no cure, people have to learn how to manage symptoms.

More information is available online from the NHS.

[Tourette's syndrome - NHS \(www.nhs.uk\)](http://www.nhs.uk)

My experience of Tourette's syndrome

I have had Tourette's syndrome since I was five years old. It was first noticed when I was flicking my head from side to side more than normal. It just looked like I was getting my hair out of my face. I was referred to hospital where I saw a consultant and specialist at hospital but was not offered any further support.

“The older I got it became more noticeable, I will always remember that it was Year 6 when it developed and got worse. I did have a chance to have time out when I was feeling overwhelmed even if it was just to sit out for five minutes.”

When I moved up to secondary school that was a big move for me. Going from primary to secondary, I had help and support along the way and they were very supportive. I was meeting all new people from all different secondary schools and for me that was very nerve racking.

As I went through Year 7, 8 and 9 (secondary school) my tics became more manageable. They are part of me it makes me who I am and that is what I believe. I have been on holiday and done karaoke and my tics have never stopped me and never will. It is a part of my life, and they will never stop me from living my life.

When they get worse like when I am nervous or excited, I just put on music and dance and let the stress go away and loosen up, dancing is a great way to loosen up and relax.

In all the years I have had tics which has been many, I have never gone to a support group, I just have had help from the teachers at school. They even gave me a red piece of paper which was known as a time out card so if I ever needed to leave the classroom and have a break I was able to do it.

How does it affect a person with Tourette's Syndrome?

This condition effects everyday life, depending on how severe it is, is how you can learn to manage it. Some individuals don't know what to do and maybe feel embarrassed and insecure to go out in public and feel like outsiders. We are all unique no matter what condition you have, you are unique and learning to manage it is a massive achievement.

“I have learnt to manage it over the years, I mean I have had looks and stares from individuals, but I take no notice because I have learnt that it is a part of me and that my life isn't going to stop just because of one thing”

My family were so supportive and I did have to go to the hospital and see a specialist but because of how much progress I had made I was discharged. I carried on my journey with support from my family, I want every other individual experiencing something like this to be able to make the same progress and get onto a road to becoming more confident, independent and being able to manage Tourette's syndrome no matter how severe it is for them.

Tourette's syndrome can be difficult to cope with but finding the correct help and support will help you more than you think, and it will enable you to live your normal life and manage it.

Depending on the individual sometimes different emotions trigger the tics more. For me its excited and being nervous that trigger mine off that bit more.

Over the years I have learnt to control it, so it is not noticeable anymore and if someone finds out they are generally shocked. But that is years of practise and mainly years of accepting this is me, this is part of me. It isn't going to stop me living my life it just helps me to accept myself more.

I spoke to someone once who had Tourette's syndrome like me and went to my school and are a lot younger than me. I met up with her talked to her about my story and answered her questions. I told her to block out individuals who bully you about it or make fun of you. Make the movements into a dance or always have a squishy with you to squeeze the life out when you are stressed, or you feel like they are getting stronger as it may help to calm down your nerves and calm them down.

Feeling anxious, nervous, happy, and excited can cause them to become more noticeable and happen more frequently. Tourette's syndrome can change, mine has, I have had different ones for years, some of them stay the same but others I start doing more and some just disappear without me noticing.

What support is available?

When it comes to support out in the community there is Tourette's Action, this is a support and research charity that work to help improve the lives of people with Tourette's syndrome. [Tourettes Action \(tourettes-action.org.uk\)](https://tourettes-action.org.uk)

The services they offer are online chats and email support, a befriender network, events, and networks for the number of years.

Tourettes Action is the only real support out there with no local support groups nearby. In Swindon and Bath and North East Somerset there isn't anything and no support available.

I have Tourette's syndrome I have never known about any groups that are out there to go to for help and support and have never attended any.

Tourette's Syndrome wasn't a widely known thing when I was diagnosed. Even though many more individuals are being diagnosed with Tourette's syndrome that are much more severe than me the support out there is lacking.

There are no posters or any advertisements for support groups for individuals suffering from Tourette's syndrome as it is not well known. But more and more individuals are being diagnosed with it and some individuals have it so severely it effects their everyday activities and they are struggling, they need the help and support.

What can be done to help people with Tourette's syndrome?

I may have been able to cope and manage the condition over the years but for others it really isn't as easy, I would love to help more people out dealing with the condition I have or similar condition, there is no real support locally outside of the hospital.

I would like to as a young Healthwatch volunteer set up a local Tourette's support group with guidance from the team at Healthwatch Swindon and Bath and North East Somerset. As part of this we will contact Tourettes Action for advice on how best to approach setting one up.

This briefing will also help raise awareness of the issue and will be shared widely within BaNES and Swindon locality and on all Healthwatch communication channels.



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