

Dear MSP,

I am writing to tell you a little bit about my life and the challenges my family face when trying to access services like healthcare, social care, and education.

Support from healthcare services, which should be easily accessible to all, are just outside my grasp due to a lack of knowledge and understanding healthcare professionals have of Tourette Syndrome. As the professionals are clearly at a loss with how to diagnose and support the Tourette's community it is clear that we are in dire need of SIGN guidelines. My family and many others across Scotland need your help to remedy this situation by fighting with us for the creation and implementation of SIGN guidelines for Tourette Syndrome.

Tourette Syndrome is a complex neurological condition characterised by motor and vocal tics and is often accompanied by conditions like ADHD, OCD, Autism and more. Tourette's affects approximately 1 in 100 people in Scotland. These are similar numbers to autism, and yet there is no government funding, and many health professionals have limited understanding of the condition or how to support people living with it.

The diagnostic criteria for Tourette's are very clear - you must have the presence of at least one vocal and one motor tic for at least a year with no break of more than three months, and these tics must wax and wane. That being said, it is a postcode lottery when it comes to the diagnostic process. We, like most families living with Tourette's, were passed from GP to paediatrician to Neurology to CAMHS with waiting lists all along the way. No single step in this journey was quick or easy, made worse by the lack of support or understanding of Tourette's. To compound our difficulties, when we finally got a diagnosis, we were offered no support or guidance about what to do next or how to cope with this complex condition.

You can imagine the needless stress, anxiety, and strain that this places on our mental health and well-being. It is exhausting constantly being misrepresented, having to fight to be heard and coming up against health professionals that understand less than we do about Tourette's.

The challenges of getting a diagnosis and the years that this takes also has a massive impact on supports in education. Many schools want confirmation of a diagnosis before they will put supports in place leaving our young people isolated, unsupported, misunderstood and identified as troublemakers. Tourette Syndrome is not something education professionals are taught about in their training and so schools have no idea how to support our young people, and many of the challenges faced are often put down to bad parenting.

Tourette Syndrome is a recognised disability, and many people face discrimination on a daily basis.

We need SIGN guidelines. We need a clear path to diagnosis. The health professionals need guidance on best and safe practise to support us and help us manage our Tourette's challenges. We need to know how to access support and we need our educators to understand and support the challenges our young people face every day. We need your support to make this happen.

If you would like more information on Tourette Syndrome, then please reach out to Tourette Scotland. Their website is [www.tourettescotland.org](http://www.tourettescotland.org) or contact them at [info@tourettescotland.org](mailto:info@tourettescotland.org)

Thank you for your assistance with this.