

Provide a clinical pathway, medical care, and specialists for people with Tourette's syndrome in Wales

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Petition Number: P-06-1249

Petition title: Provide a clinical pathway, medical care, and specialists for people with Tourette's syndrome in Wales.

Text of petition: Tourette's affects 1 in 100 children. It is not a rare condition. In Wales there is 1 specialist who doesn't see children.

Tourette's syndrome is a neurological disorder that affects the nervous system and causes tics. Tics are involuntary, sudden, and repetitive movements and sounds. Tourette's syndrome can be painful and debilitating.

Lots of people are unable to get a diagnosis due to no pathway or get discharged the same day with no ongoing medical care and support.

Tourette's isn't just swearing.

Not getting medical care and support can lead to long term mental health problems. People with Tourette's can have difficulties with anxiety, sleep, rage and social isolation.

We NEED a proper, clear, clinical pathway and access to specialist provision and medical care for people with Tourette's syndrome in Wales.



1. Background

Tourette's syndrome is a condition that causes a person to make involuntary sounds and movements called tics. Tourette's Action states that it is estimated that more than 300,000 children and adults in the UK live with the condition.

Tics are the main symptom of Tourette's syndrome, usually appearing in childhood between the age of 2 and 14 (around 6 years is the average) and can be a combination of physical and vocal tics.

People with Tourette's syndrome may also have obsessive compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD) or learning difficulties.

NHS Wales states that tics are not usually harmful to a person's overall health, but physical tics, such as jerking of the head, can be painful. The tics and other symptoms can improve after several years and sometimes go away completely.

There's no single test for Tourette's syndrome. Tests and scans, such as an MRI scan, may be used to rule out other conditions. A person can be diagnosed with Tourette's syndrome if they've had several tics for at least a year.

There's no cure for Tourette's syndrome, but treatment can help manage symptoms. Treatment is usually available on the NHS and can involve behavioural therapy and/or medicine.

Neurodevelopmental services in Wales

The all-Wales neurodevelopmental service workstream was launched in 2015/16 under the Together for Children and Young People (T4CYP) programme.

Multidisciplinary neurodevelopmental teams were developed in Wales and a Neurodevelopment Diagnostic Assessment Pathway published, which includes six standards. A guidance document on the delivery of neurodevelopmental services in Wales was also published.

In November 2019, the T4CYP Programme was extended until 2022 with a refocused remit on three key areas, one of which being neurodevelopmental services. The objective for this strand of work is to 'further support health boards to implement the pathway and standards, and to support the development of a whole system response for children and young people with neurodevelopmental conditions, providing an early offer for children and young people and their

families, who otherwise would be referred to the neurodevelopmental team'. [A Vision for Neurodevelopmental Support & Services in Wales](#) has been published by the T4CYP (2) Programme.

2. Welsh Government action

In her letter to the Petitions Committee, the Deputy Minister for Social Services states that the Welsh Government is working to improve assessment and support services for all neurodevelopmental conditions, including Tourette's syndrome, 'with the aim of building sustainable services for the future across all of Wales'.

The Welsh Government's approach will be informed by the results of a **demand and capacity review of all-age neurodevelopmental services** which was due to report at the end of March 2022. The outcomes from this review will provide the Welsh Government with information to plan long term future service improvement.

The Deputy Minister notes that work has already been done to support this goal, including the publication of the [Statutory Code of Practice on the Delivery of Autism Services](#) which came into effect in September 2021. The Code has a dedicated section on the provision of assessment services. This is being expanded to include other neurodevelopmental conditions such as ADHD and Tourette's syndrome.

The Deputy Minister has recently met with the petitioner and members of a parent support group to hear directly their experiences in trying to access services and support for their children. Welsh Government officials have also met with the petitioner and the Deputy Minister notes that they will continue to work together with the parent group as future neurodevelopmental policy develops.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.