

P-06-1249 Provide a clinical pathway, medical care, and specialists for people with Tourette's syndrome in Wales, Correspondence – Petitioner to Committee, 02.04.22

To whom it may concern,

Many thanks for letting me know that my petition is going to be considered at your next meeting on 25th April.

I have read the document that was attached and would like to express some of my views and also add some more information for the committee to consider.

I would like to raise my concerns around the fact there are no NICE guidelines for diagnosing Tourettes syndrome. This in turn means that right from the point of contact with your GP its a lottery of wether you are referred on to see another medical professional or signposted to online information and sadly people are being turned away because there aren't any guidelines to follow and because there is an absolute lack of knowledge surrounding tourettes and other tic disorders. A NICE pathway is needed to diagnose and to treat . Having guidelines would help to ensure that wherever you are from in Wales could access the care they need.

There needs to be a huge push on training from the bottom up, starting with GPs and following through to Paediatricians and education settings. The added stress from an already very stressful situation from medical professionals not knowing anything about Tourettes syndrome is awful. Through my support group I have learnt that GPs and other medical professionals are still under the illusion that Tourettes syndrome is swearing and if the person presenting with tics isn't swearing they are then saying it can't be Tourettes. This leads me on to express my view that something needs to be done to raise awareness of Tourettes syndrome and other tic disorders. There is sadly still such a huge stigma attached and alot of misinformation. Other neurodevelopmental conditions have had their profile and awareness raised massively over the last few years and with this comes acceptance and understanding. I would love to see this happen for the Tourettes Community.

Some people are being treated for their Tourettes but very often this is only coming in medication form and can often be very strong anti psychotic drugs. We would like to see treatment including both therapy and medication and this is something Tourettes Action are working hard on.

I conducted a survey within my support group and took five families from each of the health boards in Wales and the results were shocking. The health boards are all doing different things, from who you see to who is diagnosing to the time spent waiting. Even more worrying is that even within the same health board and even within the same hospital the care varies wildly.

I have been told by the chief executive of my health board Hywel Dda that they have now started providing a pathway for people presenting with tics. I have been told that the first post of call would be to Camhs and if Camhs felt there was a neurodevelopmental condition they would then refer on to the neurodevelopmental team for assessment. Camhs is

extremely hard to access as I know first hand ,after being declined three times with them before finally my daughter was accepted, you have to be in absolute crisis and actively suicidal to be accepted and even then they have massive waiting lists. I am extremely concerned that the wait to see camhs is long if you are lucky enough to be accepted and then if you are referred on to the neuro team they also have at least a two year wait. Surely this is unacceptable and again from within my group I know that Camhs are often declining people who are presenting with tics and so the families go round and round in circles with no one to help. No one knows whose responsibility it is and seemingly no one wants to take responsibility.

If someone is lucky enough to get a diagnosis there is no after care no matter what health board you come under. Many people are being diagnosed and discharged the same day which was the case for my own daughter. We would like to see ongoing support for the person and their families. Ideally we would love to see a specialist Tourettes clinic within Wales that would offer a complete care package from therapy, access to medications, help with sleep , behaviour difficulties , mobility difficulties, managing pain and help with other co morbidities. Help and support needs to be available in ALL parts of Wales. The people that would be providing these services need to be fully trained . Access to a specialist in WALES is absolutely needed.

I would also like to raise my concerns that along with Tourettes Syndrome there is very little knowledge of other tic disorders such as Functional Neurological Disorder. The two can present extremely similar to each other and indeed it is possible to have both. The problem is without proper training and knowledge there could be alot of misdiagnosing and the treatments for the differing conditions are not the same.

People are facing huge waits to see a medical professional be it a Paediatrician, neurologist or camhs and this is completely unacceptable. Tourettes syndrome is a very complex condition. Leaving people with no access to medical care is horrendous. It can lead to depression and other mental health conditions, problems accessing school/education and the workplace and social isolation which without the correct support and care in a timely manor is going to become even more serious meaning the person and very often their families are going to need even further interventions.

Thank you for the opportunity to put forward my views

Yours sincerely