

12 October 2009

Baroness Young  
Chair  
Care Quality Commission  
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Dear Baroness Young

As a member charity of the Neurological Alliance, we write to urge you to support the notion of Special Review into Neurological Services by the Care Quality Commission.

Over eight million people in England live with a neurological condition. This includes between 300,000 and 330,000 people in the UK who have Tourette Syndrome (TS) of all severities - one schoolchild in 100. Over 9,000 children and adults in the UK will be moderately or significantly physically and/or mentally disabled by their TS.<sup>i</sup> Figures are imprecise because no data on TS are collected by Health Authorities.

The needs of people with a neurological condition cut across health and social care and fit well with the remit of the new Care Quality Commission. In the case of TS, they also impact significantly on education. The quality of life in young people with TS is significantly lower across all the following areas: physical health, psychosocial health, emotional functioning, social functioning and school functioning, than in healthy young people without TS.<sup>ii</sup>

Whilst there are some examples of excellent services, they are few and far between in the case of people with TS. There is no TS paediatric service, for example, in the whole of Wales - and TS is a condition that starts typically at five to seven years. Also typical is the following complaint from one of our members.

*From the age of 16, I had been explaining my symptoms to my GP. I was made to feel I was wasting precious consultation time, and my symptoms were not worth listening to. After I was finally diagnosed, I was relieved, then depressed. I went to the hospital alone but there was no counselling so I could adjust to my new label.*

<sup>i</sup> Stern et al., (2005). *Gilles de la Tourette's syndrome and its impact in the UK*. Postgrad Med Journal 81:12-19.

<sup>ii</sup> US studies suggest that 27% of people with diagnosed TS have moderate or severe symptoms causing physical and mental health disabilities MMWR Morb Mortal Wkly Rep. 2009.



*My GP understands very little about TS and constantly patronises. It's not her sympathy I'm after, but willingness to seek knowledge for a patient she's known for over 15 years.*

*My claim for Disability Living Allowance was rejected. The questions on the DLA form apply to people with obvious physical disabilities, not someone with a neurological condition. This makes me feel like a fraud for applying.*

*I try to be positive about my TS, but when the health and especially social care services aren't willing to help, it feels as if I'm fighting a lonely battle. Asantwaa\*, 23*

Neurological conditions are rarely prioritised. A Review would raise awareness and stimulate change and we would be grateful for your support for the initiative.

Yours sincerely

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\*Name has been changed to protect identity; this person has given specific permission for their story to be used for campaigning purposes.