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## **Disinhibited Thoughts #6:**

Does Tourette Syndrome really go away in adulthood? My own evidence in dispute of this “myth”, while anecdotal, is considerable. As of late, “we” seem to be coming out of the woodwork with great speed; in fact, the parents of TS children in the Wellington-Waterloo chapter are in danger of being overrun!

Personal impressions aside, though, the research to support such a statement simply isn't there either. The few studies which have addressed the issue of outcome all agree that **TS for the vast majority of us is a life-long condition**; my own belief is that we are genetically predisposed to be disinhibited, and that quality of oneself will always remain within us in one form or another. While *some* individuals remit completely, the most the rest of us can expect is to see a reduction in our tics (which also is far from guaranteed). And, some research adds, the declining or vanishing tics may simply be “trading” with other forms of disinhibition regulation problems, such as OCD, in a seesaw kind of effect.

So how did the communication of this malicious tidbit of hogwash somehow become common practice among well-intentioned diagnosing doctors (both M.D. and Psychologist alike)? Perhaps because of generational differences: TS simply didn't exist as a diagnosis before the Shapiros' labelled the disorder in 1978. Before that time, while these adults may have indeed been categorized, the labels were less than accurate (“nerves”, “weird”, “possessed”, and the like). Because of this, there are (at least at this time in history) many children diagnosed with TS, but few adults. Hence, without an historical perspective to train the eye, it “looks” like TS must go away in adulthood.

Perhaps another reason that few adults come to the attention of clinicians is because by the time you are an adult, by necessity you have found some way to adapt, to cope in an often-unforgiving world. Since many adults were never diagnosed during the formidable years of their development, they never had the opportunity to explain away their difficulties, nor even always fully appreciate how much harder they were working than others to accomplish the same amount of work. In the absence of excuses they were forced to “Find A Way” to accomplish their goals. Hence, most of the TS adults I know are exceptional strategizers, and have a good sense of personal accountability.

Over time the person may well have succeeded in removing him/herself from the category of a “disordered individual”, but (s)he did so not by re-wiring their heads; rather (s)he developed a better “fit” with their surroundings. Creativity, discipline, a re-channelling of Tourettic energies, and considerable and effortful compromise of what they are so that they may be what our world expects them to be was what solved their problems.

To then say that the neurology has simply “gone away” in these people is insulting. It does not give due credit to their phenomenal accomplishment. It minimizes the battles these individuals still face, whether with different manifestations of disinhibition or the uniquely adult challenges TS can bring. It also robs us of two tremendously positive opportunities. The first is the opportunity for TS children, lost and confused, to benefit from the wisdom of those who have “been there”. The second is the opportunity for TS adults to, through working with TS children, to become aware of their own gains and abilities. Together as mentor and student, TS adults and children can both develop pride, empowerment, and well-earned self-esteem.

I can envision a world where TS is no longer perceived simply as a catastrophic growth phase in a select population of abysmally unfortunate children. Instead, it will be seen as one of life's curves designed to test your mettle and to forever strengthen your character, a life-long potential to be harnessed with the help of the right tutelage and eventually even celebrated. Please dream with me.

Until next time, my friends,  
Duncan  
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